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Doorway to the Deep: Memoirs of Enduring Endometriosis and Embracing Life After Loss

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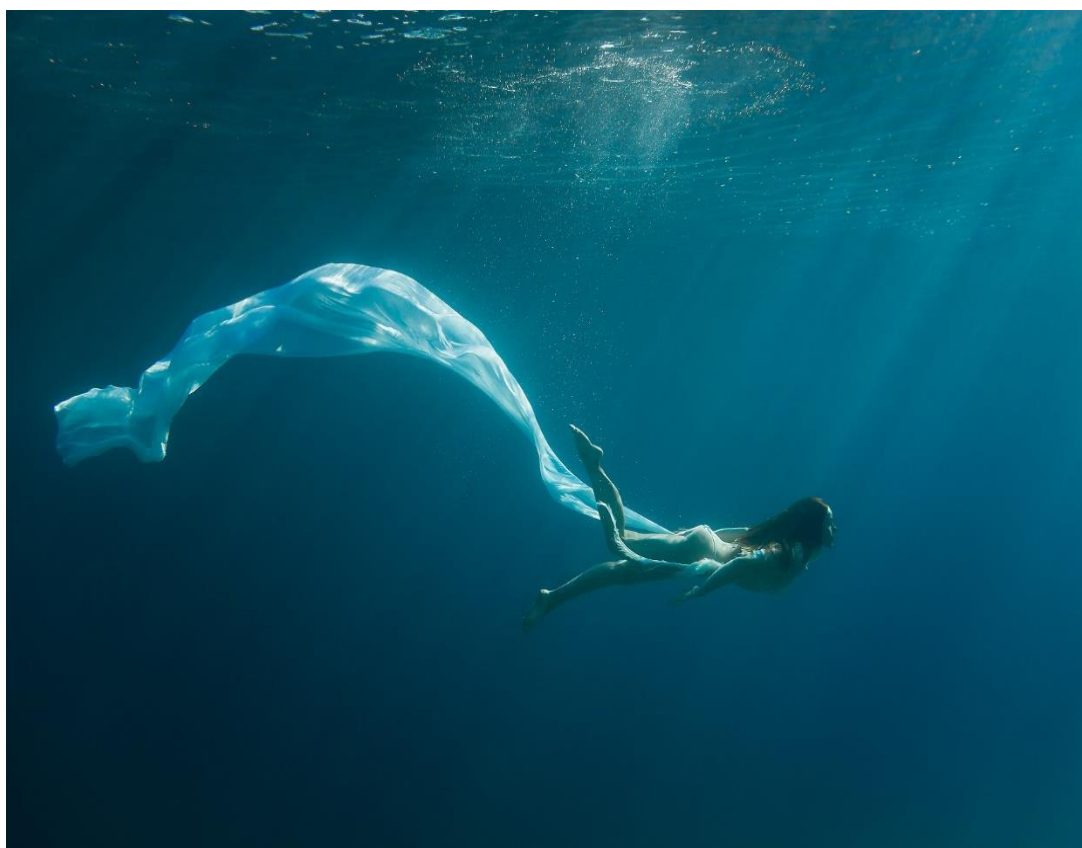
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Doorway to the Deep:
Memoirs of Enduring Endometriosis and Embracing Life After Loss

by
Carma Peña



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OVERVIEW

No one is spared grief. Yet while it is universal in nature, it is painfully specific in experience. Many people describe grief in terms of water, and often refer to it as coming in waves, while others have drifted so far from the proverbial shore that they are drowning in it. *Doorway to the Deep* explores this concept through personal reflections and private diary and journal entries.

The story commences on December 17, 1993 with my first diary entry when I was eleven years old. After enduring many years of endometriosis, the story climaxes on May 12, 2014 with my fourth and final surgery at the age of thirty-one. In the aftermath of a complete hysterectomy and bilateral salpingo oophorectomy, the story continues. Incrementally, each day, I accept the loss, release the past, embrace the present, feel hope for the future, and attempt to live authentically.

In their entirety, these entries encapsulate the highs and lows, triumphs and tears of my spiritual, emotional, physical, and medical journey. While books on the topic of grief are not in short supply, *Doorway to the Deep* offers a psychological perspective that parallels the various excerpts taken from more than twenty years' worth of writing. It is designed to be thought provoking and evoke insight into the reader's own experience with grief and loss.

The book is divided into three parts: Pre, Mid, and Post. Part one covers significant aspects of my family history and beliefs systems that later influenced my medical decisions. Part two concerns the years leading up to the diagnosis, including all the medical procedures and treatment regimens designed to preserve fertility and hope, as well as the endometriosis' profound impact on personal and professional relationships. The book concludes with part three, which describes life lived after a complete hysterectomy at age thirty-one. Each chapter includes

not only excerpts from diary and journal entries documenting this time, but also contains a psychological perspective that reflects my academic and professional background. As such, every chapter will alternate between personal memoir and professional opinion on topics such as grief, chronic pain, pain management, making helpful meaning of loss, forming healthy relationships, the interplay of spirituality and health, and women's psychological issues that can attend infertility and childlessness.

In total, *Doorway to the Deep* is projected to be a fifty-thousand-word biography that contains a bibliography and index. Upon receipt of signed agreement and advance, this manuscript can be completed within six months.

AUDIENCE AND MARKET

Doorway to the Deep will appeal to anyone grappling with grief and loss, but especially to those dealing with issues of infertility—primarily females, but also caring partners. It is a personal account of the physical and emotional passage through years of battling endometriosis. The real story begins with my very first diary entry on December 17, 1993, marking the first day of my first menstrual cycle. Time passes and the pain intensifies. Worsening symptoms necessitate increasingly aggressive treatments, each more demoralizing than the next. After twenty years of pain, several years of procedures, and no real response to countless medication regimens, it becomes devastatingly apparent that fertility preservation is no longer an option. I am then forced to make a decision about which version of myself will survive. Emerging from the operating room on May 12, 2014, I do not recognize myself. All that I can see is a broken and barren woman.

Gratefully, my story does not end there! It continues with journal entries detailing the initial aftershock of a prolonged and painful loss, and concludes with a resurgence of hope and

healing. The manuscript includes not only a personal account of grief and loss, but also contains my professional perspective as a Marriage and Family Therapist. Each personal entry will be followed by my psychological reflections, and offer therapeutic thoughts on the overall process of grief. It will also contain questions and comments aimed at assisting the reader in internalizing these concepts, and examining their own experience of loss.

Additional topics explored are suffering and spirituality, infertility and barrenness, dreams and death, mourning and creating meaning, and pain management through medical intervention and alternative medicine. Other portions of the book will be dedicated to various forms of grief such as socially sanctioned grief and disenfranchised grief; the latter of which is grief that cannot be openly expressed or publicly acknowledged. Additional inclusions will be the *Stages of Grief* by Swiss Psychiatrist Elisabeth Kübler-Ross (1969). Finally, I will incorporate the stigmatization of women of all races who cannot bear children and the comorbid issues of self-worth. All of this will be accomplished through a simple and straightforward writing style and include various pictures of artwork portraying the experience of childlessness. These will enrich the text and add a depth and dimension in ways that words cannot.

Therefore, additional audience members may include mental health professionals. Due to the nature of their work, at the heart of which is often grief and loss, clinicians working in direct care may find the themes in *Doorway to the Deep* particularly relevant. This is especially true when leading fertility support groups. Often while undergoing treatment, I would be sitting in waiting rooms next to brochures with the names and numbers of therapists offering a range of services—many of which included support groups addressing infertility. Therefore, my personal account in *Doorway to the Deep* coupled with the professional observations of a fellow mental health clinician will prove pertinent in their respective practices.

Finally, Clergy may also find *Doorway to the Deep* poignant due to the religious and spiritual components of this experience that surface throughout the writing. Many of the entries will address the requisite changes in my theology to promote adaptation, acceptance, and assimilation. Additional concepts explored include the reason or role of sickness and suffering within modern-day Western Christianity, and the importance of acknowledging the role of religion and spirituality in the therapeutic process as evidenced by a growing body of psychological research.

While my story is both solitary and specific, the reader may find that these are common sentiments shared by many people. Everyone can attest to the collective experience of grief and loss or pain and suffering, as well as the hope of life lived after dropping through the *Doorway to the Deep*.

FORMAT

This memoir will be approximately fifty thousand words and will include exercises/questions at the end of each chapter aimed at facilitating dialogue, both individually or in a group setting, on one's own experience of grief and loss. This will be marketable to anyone in a helping profession who treat issues of infertility, including mental health clinicians, medical professionals, and even clergy. The purpose of publication is dual: it is intended be educational as it pertains to the experience of endometriosis, and evocative as it addresses the social stigmas associated with this medical condition and childlessness. Endometriosis remains the leading cause of infertility in the U.S. alone, costing billions of dollars annually. And millions of women are affected by this disease, for which there is no known cure.

Outside of this community specifically, the personal elements of this story, including the diary and journal entries, will appeal to anyone's sense of curiosity, and has the potential to draw

in an even larger audience. By including themes of grief and loss, *Doorway to the Deep* has the power to attract a wide array of readerships and to captivate their attention.

Finally, the inclusion of artwork depicting the various themes of infertility will pique the interest of the audience. Some of these will be original works made specifically for this publication, and other pieces will be pictures of existing art for which permission will be obtained prior to publication. This medium is of great importance as it captures a level of pain and poignancy that words cannot always express.

COMPETITIVE AND COMPARABLE TITLES

Various genres of books addressing the topic of grief can be found on almost any book shelf; virtual or actual. To a lesser degree, the same may be said of books about endometriosis and infertility. However, *Doorway to the Deep* is unique in its combination of my personal and professional thoughts as both a survivor of endometriosis and a Licensed Marriage and Family Therapist. Each chapter will contain various excerpts from my private journals and diaries chronicling my journey from the onset of the endometriosis, through the diagnosis and treatment phases. Every entry will be offset by therapeutic insights and suggestions stemming from my background in psychology.

Other works address these topics in a mutually exclusive manner. For example, *Giving up the Ghost* by Hilary Mantel is a book which explores one woman's experience with endometriosis and infertility, but does not offer the psychological perspective. Also notable is *A Grief Observed* by C.S. Lewis which is a compilation of the author's private thoughts on God and grief in the months following the passing of his wife to cancer. Additionally, there are countless self-help books and journals related to the topic of grief and loss, not to mention the myriad of manuals on the management of endometriosis or dealing with infertility. These can range from the simple and practical management of physical symptoms, to the complex spiritual and

philosophical questions born of the inability to conceive or sustain a pregnancy. However, none combine the longitudinal perspective of *Doorway to the Deep* which synthesizes twenty years' worth of journal entries outlining the process by which I endured and slowly overcame, the physical, emotional, and spiritual ramifications of a prolonged battle with endometriosis within the framework of psychology and marriage and family therapy. Those willing to endure the pressure and pain of the "deep places" may find, as I have, healing and hope.

PUBLICITY AND PROMOTION

One in ten women are impacted by endometriosis, often rendering them infertile. This is to say nothing of the grief that follows in the wake of childlessness. Often the individual is left grappling with very real losses. These sentiments are dichotomous in that they are both universally shared and painfully specific. Due to the prevalence of these topics, there is no shortage of people whose experience mirrors my own; many of whom would be willing to write blurbs for inclusion in *Doorway to the Deep*.

To ensure publicity, I will begin by contacting my alma maters Oral Roberts University and Kennesaw State University to request publication within their online magazines. Thereafter, I will reach out to *Charisma*, *Psychology Today*, *Health Psychology*, *Spirituality and Health*, and *Behavioral Medicine Journal* to request promotion within their print and digital magazines. As a licensed clinician in Oklahoma, Texas and Georgia, I will also contact my respective licensing boards, as well as the American Association of Marriage and Family Therapists to ensure circulation among my professional colleagues. To this end, I will submit my work in the form of a proposal to the Professional Education Systems Institute to request consideration of a certified education unit training for medical and mental health professionals on the topic of grief and loss within the context of infertility and its medical, physical, and emotional impact. Other avenues of

promotion include social media: Facebook, Twitter, Instagram, Pinterest, Tumblr, etc., and creating a blog referencing *Doorway to Deep*.

ABOUT THE AUTHOR



Carma Peña has an educational background in theology, psychology, and writing, and a professional background in both direct and managed care settings as a marriage and family therapist. In 2004, Carma matriculated from Oral Roberts University in Tulsa, Oklahoma with a BA in Theology, and again in 2007 with an MA in Counseling with an emphasis in Marriage and Family Therapy. Between 2007 and 2010, she worked under supervision with various populations (many or all of whom dealt with issues of grief and loss) to become a licensed Marriage and Family Therapist in Oklahoma. After obtaining the necessary hours, demonstrating competence and proficiency in clinical matters, and passing both a written and oral exam administered by the Oklahoma state board of Marriage and Family Therapists, Carma became a licensed clinician.

New professional prospects began to surface thereafter, most notably in the form of an offer to work in the field of managed care at the largest behavioral health company, and the thirteenth largest corporation in the US. Since that time, Carma has been promoted, gained clinical skill, and diversified her psychological expertise through training in best practices for an array of mental health and substance abuse disorders. This role also involves coordination of care with various licensures including master's level therapists, Ph.D. and Psy. D. clinicians, as well as MD providers. Currently she is in a supervisory role for a national team of clinicians who manage the benefits for members whose dependents have been formally diagnosed with autism, and are actively receiving Applied Behavioral Analysis treatment.

Over the past seven years with this employer, she has transferred from Oklahoma, to Texas, and finally to Georgia, where she currently maintains an active and unrestricted license as a Marriage and Family Therapist. In addition to her full-time position, she has provided counseling and psychological services to individuals, families, and couples via private practice, and conducted pro bono counseling in a church setting.

Most importantly, Carma has experienced first-hand the pain of endometriosis and infertility. She has spent the past twenty years chronicling the spiritual, physical, medical, emotional, and psychological journey from symptom onset and history, to complete hysterectomy at age thirty-one. While writing has always been a passion, and something for which she demonstrated natural proclivity, Carma is now honing her skills by pursuing another MA; this time in Professional Writing through Kennesaw State University. Concurrently, she works as Graduate Research Assistant for the Graduate School of Nursing at Kennesaw State, providing editorial assistance to faculty on their scholarly research projects and proposals on their path to publication. On May 9th, 2017, Carma will complete her degree, graduate with high honors, and earn an MA in Professional Writing. This lends credence to the aforementioned credentials, and demonstrates the high level of personal and professional competency she will bring to bear when completing this manuscript.

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Part 1: Pre

Chapter One: The Pattern: Foreshadowing

The journal entries begin with the dream—although, it has recurred too many times to be classified as a dream: it is, more accurately, a nightmare. Each iteration brings about the same level of terror, never more and never less, and the scene does not become clearer with time.

Standing at the base of the enormous rusty, wooden roller coaster leaves me nauseous and sick with fear. Suddenly the dream will switch, and I am a passenger on the never-ending roller coaster. The car drops again and again into oblivion. It is one of only two times in my life when I am haunted repeatedly by the nightmare. In this case, it not only reflects the difficulties of the time, it also casts long shadows over my family's future.

Family stories begin with great-grandmother who died of a preventable infection only two days after giving birth to her daughter, Georgia Mae. Georgia eventually grows up, marries her sweetheart, and carries five healthy children to term, two of whom are daughters, Lois and Kayla. The sixth and final conception ends in a miscarriage. Lois, the older of the two, grows distant recounting the story; somehow still stuck in that traumatic time when, as a young girl, she is left mopping up pools of her mother's blood off the bathroom floor. Unfortunately, things do not improve for my Aunt Lois, my mother Kayla, or my older sister Leilani. One by one, each succumbed to endometriosis and its devastating effects.

In light of the family foreshadowing, this chapter addresses the long-term psychological effects of witnessing loved ones suffer, and the internal and external reactions suffering can evoke. Mental health professionals often say that there is no such thing as irrational behavior. Everyone's actions or inactions make sense to them, even if only in part. Repeated exposure to upsetting stimuli, whether environmental or interpersonal, can lead to the experience of vicarious traumatization. In essence, by witnessing all of the women closest to me struggle so painfully with issues of fertility, I am a passenger on that endometriosis roller coaster long before I start my menstrual cycle on December 17, 1993.

Chapter Two: Faith, Fear and Fractals

Chapter two examines the specific dynamics of faith and fear that have colored my fertility journey. Initially, all journal entries are filled with solitary shades, mostly black and white. Growing up in a dichotomy of good and evil, I come from a long family line of pastors and parishioners, yet great difficulty and abuse thrived in my home. It is no wonder I sought solace in a God, who I believed could have only good things in store for me. This is especially true regarding my beliefs about healing, and the tenacity with which I hold onto the hope of having escaped endometriosis. My prayers and promises to God often carry the same tenor as that of a young couple, passionately in love, who make marriage vows they cannot begin to comprehend. It is only through the passage of time and slowly declining health that the crisis of faith and fear eventually come into view. Only then do I begin to understand and conceptualize my journey in fractal form—an infinitely complex and dynamic pattern which is created by repeating the same process over and over in an ongoing feedback loop—not entirely different from the roller coaster in chapter one.

The psychological perspective in this chapter will address the cross roads of spirituality and health, as well as their reciprocal relationship. Over time there have been an increasing number of studies demonstrating the importance of spiritual connection when dealing with issues of illness. However, religion and spirituality can become unhelpful when addressing, avoiding, or coping with sickness; this will also be addressed in chapter two.

Part 2: Mid

Chapter Three: Hard Pill to Swallow

Regularly there has been an inordinate amount of pain with monthly cycles, and even a few times a year when I am debilitated. However, when I turn twenty-seven something switches.

I spend three weeks out of the month bleeding and the pain persists longer. Something is not right, but no doctor seems much concerned. I am placed on multiple birth control regimens to manage the symptoms and improve my quality of life. That is when the real trouble starts. All too soon, I discover that I am medication resistant with any and every birth control. Each provides temporary relief only to leave me with worse symptoms within two-to-three months. By the time I am able to find an excellent doctor and fertility specialist, I am diagnosed with endometriosis, which has already progressed to stage three of four. Consequently, journal entries in this stage are twisted by pain, frustration, and exhaustion.

Therapeutic thoughts on this chapter explore the relationship between medical conditions and mental health. Over time, there is an immeasurable impact on the mind as a result of knowing that something is physically awry and yet undiagnosed, or incorrectly diagnosed. As I discover, the pain of finding something wrong is eclipsed only by the pain of finding nothing at all. Being told that my symptoms are psychosomatic is demoralizing and dehumanizing. In addition, the mere presence of near constant physical pain is mentally, emotionally, and spiritually draining.

Chapter Four: Professional Purgatory

In the midst of these medical upheavals, I am licensed as a marriage and family therapist. Up until now, I have worked in outpatient settings for various mental health agencies in the greater Tulsa area. For the most part, employers have been gracious regarding doctor's appointments and occasional absences, allowing me to flex time and work an adjusted schedule. However, when offered a position in managed care at United Behavioral Health, those concessions become a thing of the past.

When my first day in the new position rolls around, June 21, 2010, I have relocated to Houston, TX. I have undergone a successful surgery on March 26, 2010 to remove the endometrium. Thereafter, I am prescribed six months of Lupron Depot, which effectively places me in a medically-induced menopause, and I experience great relief from the symptoms of endometriosis, having traded them for those of a menopausal woman. The move to Houston means new doctors, and new doctors mean new medication regimens to which I am unresponsive. This in turn means countless doctor's appointments, ever-increasing expenses, and extreme pressure from my employer. Before long, I experience the brunt of professional scrutiny bordering on harassment, and am often told by my boss to disregard medical advice and have a hysterectomy. It goes without saying that the writings of this time period demonstrate a growing darkness and depression as the limitations of the medical community are becoming apparent, and the support of my employer is wearing thin.

This chapter will address over-arching themes such as organizational interpersonal psychology and its impact on the mental and physical health of employees. Studies show that following the economic downturn of 2008, fewer employees are producing more work. In essence, fewer employees have been producing more for less pay. The addition of any extenuating circumstances impacts job attendance and performance, which in turn, elicits unwanted attention from employers, who themselves experience pressure from stockholders, etc. As that pressure increases, the body is impacted and health is compromised, creating more of the same.

Chapter Five: Relationships Redefined

It is a problem of numbers really. National averages indicate that the mean age of marriage for women in the U.S. is twenty-five. Technically speaking, I am behind the curve.

While this is not necessarily problematic for *me*, infertility *is*. Endometriosis is the leading cause of infertility in women. While it can be present from the very first menstrual cycle, women are typically not diagnosed with endometriosis until ages twenty-five to twenty-nine. As my mother and sister conceived before this time-frame, they were able to carry not all, but most of their children to term. My Aunt Lois, who first conceived in her late twenties, miscarried the child, and had a complete hysterectomy by age thirty-one. At each doctor's appointment, I am asked the name of my partner and when I was planning to have children. Unsurprisingly, dating becomes a numbers game, but not in the typical sense of the term. It is a race against time and a biological clock that with each tick, obliterates another opportunity to have children.

The psychological portion of this chapter deals with women's psychology. As a therapist, I explore the social expectations surrounding motherhood and the role of women in society. I also include the social stigma attached to childlessness, and infertility. Much will be said of the profound impact that this has on self-worth and the subsequent decisions women make in relationships. Other topics addressed in this section are the challenges of dating and being in chronic pain. Often the partner has little to no understanding of how to respond to the pain of a woman with endometriosis or to honor their periodic inability or unwillingness to be intimate.

Chapter Six: Entre Mundos: Holding Out Hope

As the title implies, at this point in time, I am still holding out hope of maintaining fertility and some sense of functionality despite worsening pain and symptoms. However, as the journal entries imply, I am "entremundos," or between two worlds. One foot is still firmly planted in faith and optimism, and the other has begun to sink into fear and futility. I attempt increasingly aggressive treatments not only for the endometriosis, but also for the growing pain, which is constant. Medications have numbed my mind but not my body. Problems with other

bodily functions arise, necessitating another surgery, as there is now concern that the endometriosis has entered the colon. Post-op pictures no longer nauseate me as they once have, and I remain eager to try new things to manage the symptoms. With each failed medical intervention, however, my weight begins to shift from one foot to the other.

This therapeutic portion will address the psychological effects of managing an ongoing medical condition for which there is no definitive prognosis. For example, when I would inquire about the probability of having children, medical professionals would respond, “Your chances are as good as any other woman in your same condition.” It was a noncommittal response based on malpractice insurance stipulations and the fact that medicine is not an exact science.

Another important topic to be covered in this section is disenfranchised grief. This is grief that is not socially accepted and cannot be publicly acknowledged. Often in cases where there is no clear verdict, grieving seems premature. Due to their own level of discomfort, friends, family, and others often try to assuage these sentiments by offering platitudes as vague as the one mentioned above. This in turn can increase a woman’s inner turmoil as she begins to turn inward and blame herself for what is actually a normal and natural process of holding hope and hopelessness in a terrible tension.

Chapter Seven: And Exercise in Futility/Infertility

By the time June 2013 rolls around, I have made the decision to transfer to Atlanta, GA with my company. My sisters are there, and on the heels of a breakup, it seems like a great idea for a fresh start. Before I leave, my fertility doctor has devised a medication regimen that would provide the longest period of symptom stability I have known since before being diagnosed. Unfortunately, by the following November the pain and symptoms have returned with a vengeance. Several interventions are performed by my new fertility doctor in Georgia before yet

another surgery is scheduled in February 2014. I no longer go into these with any hope of recovery, only the expectation of mild reprieve. So when I awake in worse pain, I knew the journey is ending. It is one of worst months I can remember. After being referred to an OBGYN surgeon, I schedule the appointment. I begin crying almost as soon as he walks into the examination room. After reviewing my medical history, he is willing to perform the hysterectomy and bilateral salpingo oophorectomy even though I am only thirty-one years old. The pelvic ultrasound tells the story. Suddenly the world falls as flat and grey as the screen displaying my distorted organs.

Grief and loss are addressed extensively in this chapter. It not only includes the specifics of medical-related grief, but also a more general concept of loss. Topics such as the impact of an “assault on our assumptive world” or people’s assumptions regarding life as well as unspoken expectations about which they may or may not be aware are discussed. Often one is not cognizant of the presence of these assumptions until something happens contrary to them, and the person is left with cognitive dissonance and important decisions to make about how to move forward with the what’s left of life.

Part 3: Post

Chapter Eight: Death and Dying

I originally schedule the surgery for July. I want to move to Kennesaw to be closer to family and near school before undergoing a complete hysterectomy and bilateral salpingo oophorectomy. Unfortunately, I cannot wait that long. Worsening pain and symptoms cause me to move the surgery up to May, which is the soonest my mother can come and stay with me post-op. Almost as cruelly as it begins, the surgery ends the day after Mother’s Day. I had been in a

constant state of free-fall for far too long, and by now I believe I will die when I hit the ground. And for the first time, I want to die. Anything seems better than this. Gratefully, I do not die alone. My mother arrives and takes me to the hospital on May 12, 2014, just in time to watch child-bearing Carma die of natural causes.

Therapeutic thoughts in this section include those on grief and loss specifically as they relate to infertility. This chapter discusses the emotional, psychological, and spiritual aspects of barrenness—especially following a long battle to maintain fertility, at great financial and physical expense. In addition, the topic of childlessness is covered. Countless times I have been asked by treating medical staff if I have other children, as if that, in some way, might alleviate the suffering. In this context, the subject of sympathy vs. empathy is discussed. By virtue of their carelessness, even the most well-meaning of individuals dismiss or invalidate personal experience.

Part 1: Pre

Chapter One: The Pattern: Foreshadowing & Family History

I lay there, almost sick with fear. My mouth was dry; all the moisture beading on my lower back arched against the exam table. “You’ve done this a thousand times,” I reassured myself, trying to calm my chaotic mind. But I hadn’t. This was a new doctor, and this, yet another procedure. It was a referral for consultation and a Diagnostic Hysteroscopy¹ from my fertility doctor. The dreaded referral.

Over time, I grew so tired of telling and retelling my personal and family medical history, reading the same dismissive, piteous, or foreboding responses in their faces. How could I possibly quantify in a fifteen-minute consult years’ worth of time and money invested in countless medications and medical procedures attempting to maintain this elusive notion of fertility? That is to say nothing of the emotional toll the prolonged battle with endometriosis was taking on my body, and even less of the generations before me who suffered similar fates. Perhaps the years were *wasted* in trying to preserve fertility and functionality. How could I clarify something I wasn’t even entirely sure of myself?

Momentarily I entertained the idea of leaving before the doctor arrived. I was fairly certain *he* wouldn’t mind a few extra minutes of free time in his busy schedule. Unfortunately, the existential crisis was not the only war raging within in me, a growing body of endometrial symptoms was emerging that could not be managed with birth control, cured with surgeries, or suppressed with pain medication; and by now, the pain and bleeding were unending. I had to

¹ Hysteroscopy is a procedure that allows your doctor to look inside your uterus in order to diagnose and treat causes of [abnormal bleeding](#). Hysteroscopy is done using a hysteroscope, a thin, lighted tube that is inserted into the vagina to examine the cervix and inside of the uterus. Hysteroscopy can be either diagnostic or operative. <http://my.clevelandclinic.org/health/articles/what-is-hysteroscopy>

know why, so I decided to stay in the stirrups where the nurse tech left me waiting, staring anxiously at the door.

Just then the door swung wide and the new doctor and nurse entered with their equipment. After the standard awkward greetings that accompany gynecological procedures, I laid back uncomfortably on the table and stared hard at the ceiling, systematically counting the tiles, trying to forget.

It was only when the procedure began that forgetting went from unlikely to completely unrealistic. The pain was so intense that I broke out into a sweat all over my body. Gripping the table I remained silent, fearful that any vocal utterance would only increase the agony. After a few moments passed, I recall the nurse sheepishly stating that the hysteroscope had been inserted incorrectly and needed to be removed and reinserted. The procedure drug on for what felt like a lifetime. In those moments, for the first time, I tried not to forget, but to remember. Why? Why was I doing this? Why was I here? There had to be a better explanation than the ones that the medical community could provide, and certainly better than the “explanation of benefits” or EOBs sent by my insurance company that were lying in stacks on my desk at home.

Home! How was I going to get there? I had driven myself to the doctor’s office, but I was left debilitated before the procedure was even complete. I vaguely recall the doctor telling me to lay there as long as I liked.

After approximately half an hour went by before I was able to get up, get dressed, and walk painstakingly down what seemed to be the never-ending corridor. At that point, even ‘remembering’ was reduced to repeating the same phrase over and over. “You can make it home. You can make it home.”

That night, lying in my own bed at last, I once again dropped through reality into the dream. The sound and sensation would always precede sight. I could feel the grass between my bare toes. My feet were small; I was a child.

My feet felt it first. Initially it was only a distant rumble. My eyes lifted as realization dawned and terror made all movement maddeningly slow. I was once again standing underneath an enormous, once-white, rusty, wooden roller coaster. There was always a utility shed directly in front of me; the kind used for repair and maintenance equipment. Innately I knew I was not supposed to be here. Clearly this was a restricted area for authorized personnel only.

As my eyes found focus, the once frightening rumble, grew into a roar as the car rushed over my head on the tracks. Dread began to build into frenzy because I knew exactly what was coming next. Suddenly, the dream would switch and I was a passenger on the car. That is when the never-ending ride began.

I rushed up one steep incline only to drop down a ravine so steep I could not see the bottom. Motion-induced nausea mixed with fear over took me. My head and neck ached with whiplash. I was continually thrown about the car at the whimsy of the controller whose face I never saw. In fact, I was completely alone. In retrospect, I am not sure if the solitude made the experience more or less frightening, but there was no time to digest that information in the dream because this ride would not stop after the average two-to-three-minute duration. It would last until I was thrown from the car back into reality.

Heaving and sweating, I awoke. Why so many times? What did it mean? The dark room was suddenly filled with all the unanswered questions I avoided just to make it through another day. Tears began to make their way down my face. Staring into the darkness, I began silently

praying for comfort and clarity. In that moment, her name slowly surfaced in my mind. Ruby Mae.

I rose from my bed. Taking my journal with me, I headed into the living room. In order to fully understand the connection between great-grandmother Ruby Mae and my current situation, (and likely because I am a clinician by profession), I began meticulously constructing a mental genogram² of my family.

Ruby Mae

“She had a very lonely childhood.” That is one of the few things I know for sure about the early years of my grandmother Georgia Mae, namesake of her parents Ruby Mae and George Harris. She would be their second child and only daughter, and her birth would herald her mother’s death. As the stories went, three days after the delivery, Ruby Mae died of a preventable infection.

Georgia Mae’s first daughter Lois would always grow distant as she recounted the story of her grandmother’s death; hands alternating anxiously between her lap and smoothing the fabric on the armrests of her favorite recliner. How many times had she heard it from her mother growing up? Or better yet, how many times had all the women in the family replayed it on a neurological loop in their minds? All I knew for certain is that in her death, Ruby Mae gave birth to what would become a long blood line of bleeding and often barren women.

Georgia Mae

By the time I was old enough to hear these stories and understand their importance, my grandmother had endured that “lonely childhood” in the care of her beloved spinster Aunt. Grandma’s father remarried and had three other sons. The stories disagree about why granny

²Genograms are family maps that can highlight historical and current patterns in interpersonal relationships and major events.

didn't live with them. One thing is certain however; grandma would eventually become a wonderful mother.

Georgia Mae grew up to marry her sweetheart, whose own childhood was marked by the loss of a parent. In fact, they both lost a parent the same year. Grandpa's father died of double pneumonia only two short weeks after an angel appeared to him in the cotton fields where he was working as a sharecropper in Conway, Arkansas. As the story goes, the angel warned him to, "set his house in order because he was going to die." The year was 1927, and grandpa was only two years old when his father passed. It was the very year grandma was born. Strange and sad to think that grandpa would eventually lose his beloved Georgia Mae to the pneumonia eighty-three years later. Their love story will always be foundational to my family and a hallmark in my history.

"He was out of town when it happened." My aunt was referring to granny's miscarriage. By this time, grandma and grandpa had been married seventeen years, since May 18, 1948—not long after grandpa finished his final tour of duty as a merchant marine in World War II. They had entered the ministry together, and grandpa was a pastor in the Bible Missionary Church, an offshoot of the Nazarene church. They moved frequently, often pastoring churches in which they received little to no salary. Grandpa often worked during the week to provide for his growing family, which included five children. Often this meant working out of town and commuting.

Sometimes it seemed he had been working his whole life, or at least from the moment his father died. He was among the most tender-hearted men I have ever known. My grandpa would tear up recounting both the hardships and happiness of his childhood in Conway. It seemed to bring him great comfort during times of intense homesickness when, at the age of fourteen, he left home to work in the Civilian Conservation Corps, later known as the CCC camps, which

were developed by President Franklin Roosevelt to increase jobs and stimulate the American economy. Attempting to help grandpa's mother, who was by then widowed and attempting to raise seven children during The Great Depression, the county official lied about grandpa's age to ensure entry into the program. He sent every dollar straight home. Nothing ever changed in that regard. Everything he did was for faith and family. At that thought, more memories and tears spilled out and spread across the pages of my journal.

By the time my grandparents had five children over a ten-year span from 1949 – 1959, they had no real plans of expanding their family any further. So, news of another pregnancy came as a shock. They were living in Chandler, OK when grandma began to miscarry. My mother, the youngest of the five, was in the first grade and only six years old. Aunt Lois, the third of their children, was twelve years old, and by default, became responsible for taking care of her mother; a role she would continue to play with great ambivalence until grandma passed away in 2010. There was no real preparation for this position, only initiation, and it came the day grandma summoned her to restroom, bathed in blood, asking her to call for help. Eventually the ambulance came and carried grandma away while Aunt Lois mopped up the mess and tended to her distraught younger siblings. The pregnancy ended as shockingly as it had begun.

Lois Ann

Aunt Lois' fertility story is the one which my own most closely mirrors. While not the same, they are not as easily distinguishable as I would have hoped. Then again, there are still many pages remaining to be written in both of our lives.

It all began with her mother's miscarriage. In those terrifying moments, she transformed from a child to an adult, responsible for the welfare of her mother and younger siblings. At least that is how it seemed the countless times she recalled the event. Certain things can never be

unseen, and watching your mother miscarry is among them. Eventually grandma returned home safely. The fetus did not.

Aunt Lois' menstrual cycle began unremarkably around age fourteen. She often talked about how you could "set a clock by it." It may as well have been referred to as "Old Faithful!" There was nothing about it that would forewarn her of the horror that lay ahead. In retrospect, maybe that was an act of divine mercy.

She fell in love and got married at twenty-six years old; often describing nothing but marital bliss in the early years of her marriage. Not long after her wedding day however, she began experiencing severe pain with menstrual cycles. Initially she didn't think much about it, other than trying various forms of birth control to manage the symptoms as prescribed by her gynecologist. The pain worsened over time and she began periodically missing work. This effectively placed her under professional scrutiny as she was an accounting manager at a firm in downtown Houston ironically named Property Management Systems, or PMS!

Concurrently, she and her husband began trying to start a family of their own. It would take months and months to conceive in the midst of worsening pain and symptoms, during which time she remained undiagnosed. Some medical professionals even went as far as to tell her that the pain was all in her head. So by the time she became pregnant, and miscarried three months later, it was glaringly evident that something was really wrong. Like her mother, she would nearly bleed to death in this process.

She used to cry recounting this time. Speaking wistfully or wincing painfully, Aunt Lois would recall the reactions and comments of friends and family to the miscarriage. In some ways it is still painful for her, but not in the way it once was. However, like Jacob's wrestling

encounter with God that left him forever walking with a limp, Aunt Lois will move throughout the world differently because of her miscarriage (Genesis 32: 22-32).

By the time she was finally diagnosed with endometriosis³ its devastating effects had already twisted her pelvis in a painful new direction, and multiple organs had been invaded. In fact, the doctor could no longer perform even routine exams. She was rushed into surgery where one ovary became the second casualty in this war to maintain her “womanhood.”

Gratefully, she was able to check out of the hospital with the other ovary intact, and some hope of conception in the future. The prognosis was mixed. She and Uncle Dennis continued to try and create the family they both so dearly desired. Unfortunately, the passage of time brought only pain, not parenthood. As it grew worse, she made the decision to quit her job. The paycheck no longer compensated for the long hours and harassment she endured for attending doctor’s appointments, and periodic absences due persistent and worsening illness.

Uncle Dennis had always been Aunt Lois’s biggest supporter. He both recommended and agreed with her professional decision to quit. Therefore, when she made the personal decision to have a complete hysterectomy not even one year after the previous surgery, he stood by her side. She always weeps when telling this part of the story.

Through the tears, Aunt Lois recalls the appointment in which she made the decision to have a hysterectomy. The doctor agreed, and briefly left the room to begin making arrangements with the nursing staff. Upon his return, Aunt Lois was crying. He said something to her in that moment that she would repeat verbatim with each recall. “This does not make you less of a woman.” He then opened up and shared about his own wife’s battle with infertility. It was enough to get her through until the moment she would have a complete hysterectomy at the age

³ Please feel free to review sites such as <http://endometriosis.org/> to expand your understanding and knowledge of this disease.

of thirty-one. Far from the end of her story, this surgery only marked the end of the fight to maintain her fertility.

Terin “Kayla”

Enter my mom, Kayla, from stage left. Starting in junior high, every month like clockwork, my grandparents would receive the same call:

“Your daughter passed out again and is in the nurse’s office. You need to come and pick her up.”

Mom routinely threw-up, passed out, and experienced severe cramping nearly every month of her menstrual cycle. She continued until she, too, had a complete hysterectomy. I watched her struggle through the pain every month from as early as I can remember. While her experience with endometriosis did not mirror that of her older sister, Lois, her path was not without pain.

For better or for worse, mom became pregnant with her first child at the age of twenty-one. She was not yet married to my father, who turned out to be a drug addict. My grandma wanted mom to be married, but grandpa did not. Therefore, grandpa offered to take care of her and advised her against marriage at that time. Feeling she had committed the cardinal sin, mom married my dad, and a few months later, my older sister was born.

Nothing that my mother experienced was ever described as marital bliss. She and my father were young, from different ethnic, religious, and cultural backgrounds, and his addiction would cause ongoing chaos in the marriage. While I am still unclear on the specifics, I know that on or around my birthday, October 1982, my father was caught in the act of stealing to support his habit, and subsequently was sentenced to two years in Huntsville State Prison, right outside of Houston. My mother recoils a bit in the retelling, and that is probably why details and

timelines are unclear to me still. There are only two things I know for certain: 1) my parents' marriage never survived my father's prison term, and 2) there were no complications with the conceptions, pregnancies, or deliveries of me and my sister.

Many years passed and the pain with menstrual cycles began to steadily increase for mom to the extent that Leilani and I were both shocked when she again conceived at the age of thirty-five. She and her husband at the time had just made the decision to separate. The pregnancy was painful for her, both physically and psychologically. In an emotional upheaval about the end of her third marriage, mom wasn't entirely sure how she felt about the pregnancy until she started bleeding.

I can remember walking into the bathroom as mom began crying hysterically, wiping the blood. In that moment, it seemed as if all the women in my family were systematically drowning in a sea of blood—great grandma, grandma, Aunt Lois, and now mom. Gratefully she would not miscarry the child despite a tenuous pregnancy, and Brenna was born in October 1993.

Two years after Brenna's birth however, mom's health again declined. She was finally diagnosed with endometriosis at thirty-seven. While pregnancies serve to slow the disease, they cannot stop it. As her pain grew from terrible to intolerable, she sought medical help.

Her insurance had changed, and her new doctor wasn't convinced anything was wrong. He finally agreed to perform an exploratory procedure as a concession, not out of concern. Not surprisingly, he was an incompetent surgeon whose botched operation was scheduled for two hours and lasted six. His poor bedside manner extended throughout the recovery process, and the disease grew like wildfire thereafter.

At age forty-one it became medically necessary to proceed with a complete hysterectomy. She had reached stage four endometriosis, and it was growing down into her legs.

By the time she underwent the operation with a new and more experienced surgeon, her internal organs were so compromised that she began hemorrhaging slowly after the hysterectomy. This in turn necessitated yet another emergency surgery. Like her female forebears, she too was in danger of dying from internal bleeding.

Leilani Marie

“Are we a new generation of victims or survivors?” I scrawled in my journal thoughtfully. Depended on the day really. Maybe it boiled down to a battle of emotionality over rationality. Some days the scale tips in favor of one more than the other no matter how hard you try to maintain balance and emotional equilibrium. Leilani always seemed better at maintaining a level head than I was. Unless you jumped out of the shadows and scared her. It only took one punch to the face for me to learn to bob and weave before trying that again! If Leilani could be described as any one thing, it would be a fighter. The same could be said of her own experience with endometriosis and fertility.

She started her menstrual cycle young; barely ten years old. Like our mother, Leilani would become deathly ill every month and occasionally blackout from period pain. Her cycles were long and she bled so much there was concern of hemorrhaging even then. Mercifully, her clinical presentation isn't entirely bleak.

At twenty-five Leilani had already been married for seven years. She eloped at eighteen a boy she fell in love with while working side-by-side at Chick-Fil-A. They grew up together, became financially stable, and wanted to start a family of their own. She'd been diagnosed with endometriosis, but it had remained largely manageable.

Initially, Leilani easily conceived and carried to term a son. It was only when they attempted a second child that the trouble began. She was still in her first trimester when she started bleeding. Gregg immediately took her to the ER, but they could no longer find a heartbeat for the unborn child. Leilani continued bleeding throughout the night and lost the baby the next morning.

About one year thereafter, Leilani was again able to conceive. Nine months later she gave birth to a daughter. While Leilani still deals with difficulties related to the disease, she is a fighter and a survivor.

Carma Liane

Which brings me to my own humble beginnings. I both feared and longed for the day when I would start my menstrual cycle and “become a woman.” Much like adulthood, no one tells you just how much of a scam womanhood turns out to be. About two months after the birth of my little sister, Brenna, it was my turn to begin bleeding. Clearly, I was ecstatic because my Lisa Frank diary/planner combo contained big bubbly letters and my very first entry. It reads: “This day is really special for 2 reasons. Today is really special because I started my period! AND Today school is letting out!” Five days later, I had to record the end of the beginning: “Today I stopped my period. I’m relieved. I mean, it’s exciting but it can be gross.” It was of no consequence to me that Kevin Scott skated a world record that day, or that Northern Exposure star Barry Corbin fell off his horse, or even that the number one song in America was “All for One,” by Brian Adams. By God, I had started my period! I was a woman, and you could hear me roar!

~ Psychological Insights & Therapeutic Thoughts ~

Making Meaning of the Mess

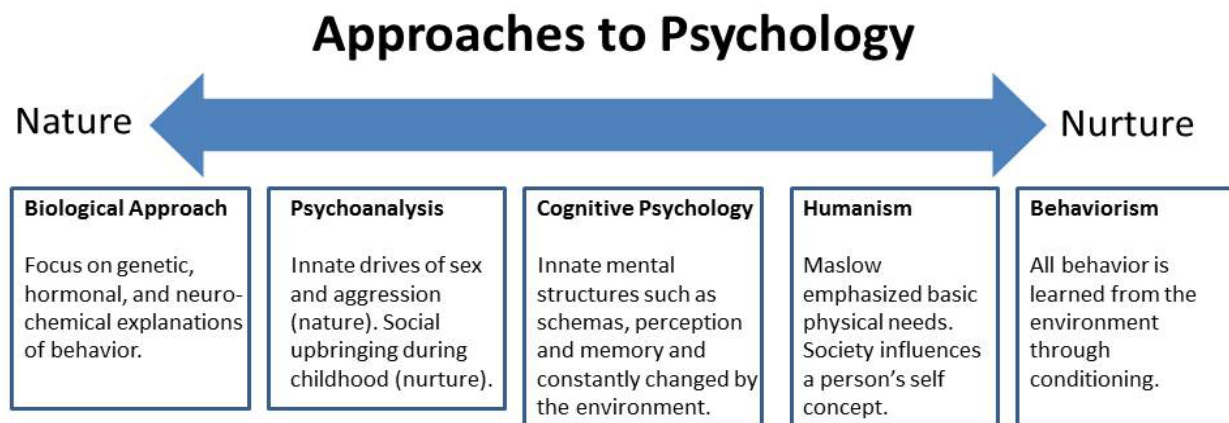
As a therapist I recognized the importance of exploring the psychosocial history behind my actions, inactions, and reactions to the endometriosis—even if initially resistant to introspection. That is not to say that endometriosis is not, in and of itself, infinitely complex, often misdiagnosed, and challenging to treat. Rather, I understood there were additional factors at play including a long family history of fertility issues that informed and influenced the way in which I viewed myself and my function in the world. Without this knowledge, there would be no understanding the reasons why I made some of the choices I did. And without understanding, I could not draw from my family's strengths or learn from their weaknesses.

Years of watching the women I loved and looked up to suffer profoundly impacted my sense of safety and well-being. In fact, the importance of attachment to caregivers starting in infancy cannot be overstated. This connection remains vital throughout childhood and into adolescence. Entire worldviews are created through these connections (Nichols & Schwartz, 2006). According to The National Child Traumatic Stress Network, it is in the context of these relationships that, “children learn to trust others, regulate their emotions, and interact with the world; they develop a sense of the world as safe or unsafe, and come to understand their own value as individuals.” In fact, it is only when those relationships prove unstable or unpredictable that children begin to believe others aren't reliable and cannot be counted upon to help them. All of this is based upon Attachment Theory.

Among the countless ways of viewing the world, Attachment Theory provides a unique lens through which relational dynamics can be understood and treated. The following illustration was taken from the work of author Sam McLeod in his article entitled, “Nature vs Nurture in

Psychology.” This graphic is a distributional model outlining various perspectives on human development ranging from biology or nature on one end of the spectrum, to behavior or nurture on the other. Each theoretical viewpoint has merit and can provide useful information as it pertains to better understanding human behavior.

Table I



John Bowlby, the developer of Attachment Theory, was a British psychologist, psychiatrist, and psychoanalyst who lived from 1907 – 1990. In short, Attachment Theory is a psychological theory which provides a framework for understanding interpersonal relationships between human beings. To formulate a comprehensive theory, Bowlby pulled from an array of fields including object relations theory (psychoanalysis), evolutionary biology and ethology, cognitive psychology, and control systems theory, just to name a few (Chettiar, 2013). Obviously, he too understood the value of various approaches and incorporated many of them into Attachment Theory.

After Bowlby pioneered this theory, others began to build upon his legacy. Most notable was Mary Ainsworth, who postulated that children often used the primary caregiver as the “secure base” for exploration. In most cases, this person was identified as the mother. When

feeling threatened, the infant would return for protection and comfort. According to Nichols and Schwartz (2006), “Infants with secure attachments are confident in the availability of their caregivers and, consequently, confident in their interactions with the world” (p.99).

Unfortunately, this confidence is not visible in infants who have an anxious attachment. These children can often remain anxious about caregiver availability throughout their entire lives. In fact, Bowlby believed “that because attachment relationships are internalized, these early experiences shape expectations for later relationships of friendship, parenting, and romantic love” (p.99).

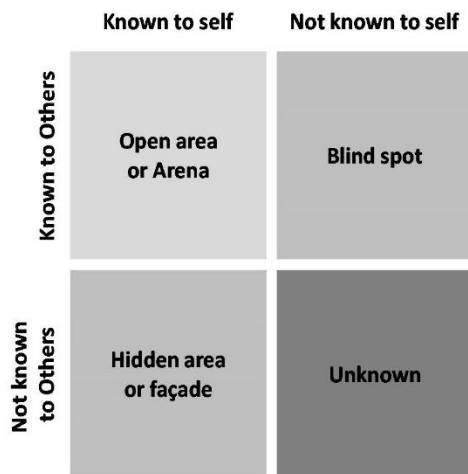
Having thus said, the introduction of traumatic events during these crucial developmental stages can not only leave an indelible emotional and psychological mark, it may also disrupt attachment. It is not uncommon to hear the phrase, “perception is reality,” particularly when referring to an infant, child, or adolescent. Anaïs Nin said it best, perhaps “We don’t see things as they are, we see them as we are.” This may explain why children often blame themselves for things such as parental separation and divorce. In some cases, children even develop magical thinking in reaction to traumatic events. For example, my sexual abuse prevention training included the case study of a little girl who was first sexually assaulted by her father on a camping trip. She assumed it had something to do with the fact that both the sun and the moon were simultaneously visible in the sky that day.

Building upon the premise of a perceptive reality, it is also important to remember that traumatic events can be of many types and are not restricted to neglect, domestic violence, and sexual abuse or assault. A broader understanding and acceptance must be adopted. In my clinical work with children, I discovered that one of the most overlooked losses involved something as simple as moving. The process of relocating meant the loss of friends, school, teachers,

sometimes pets, and quite often both a social and religious community. Children can also experience medical trauma, school and community violence and bullying, traumatic grief over the loss of parent or sibling, and complex trauma arising from repeated and prolonged exposure to a combination of traumatic events over time.

To tie this information regarding the psychological Theory of Attachment into my family history, I propose that my own trauma arose from either hearing about or witnessing first-hand the profound fertility-related issues faced by the women in my family. It all began with my great grandmother Ruby Mae who died only three days after my grandmother, Georgia Mae, was born. She was left to be raised by her Aunt and lead the “lonely life” that is always recounted by her children. This upbringing undoubtedly influenced the way in which she parented her two daughters. It also influenced the manner in which my mother, Kayla, parented her three daughters, and the ways in which we have faced and fought through fertility issues of our own.

Tables II & III



The Johari Window Model

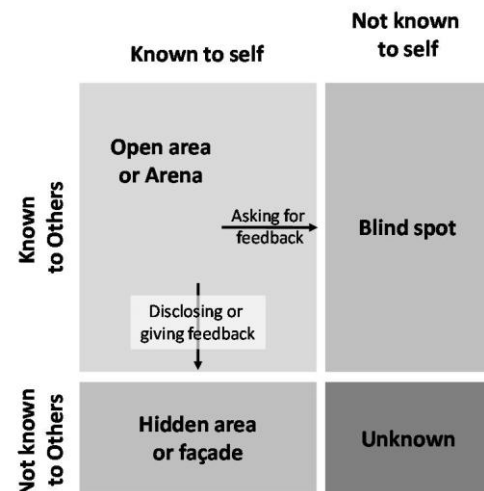


Figure 2

In the therapeutic community, there is a saying, “There is no such thing as irrational behavior.” Everything we do as human beings has relevance and makes sense to us personally—

even if only in part. Arising out of Communication Theory, American psychologists Joseph Luft and Harry Ingham developed the “Johari Window;” derived from combining their first names together. Its purpose is to enhance individual perception of self and others and is based upon two ideas: a) trust is acquired through personal disclosure to others, and b) increased personal awareness arises from their feedback. That said, the more we form reciprocal relationships built upon open and honest communication, the higher the likelihood that any rupture in the development of early attachment may be repaired and resume its vital and foundational work.

Ultimately, the purpose of this portion of the chapter is to shed light upon that fourth quadrant and unknown area, so named for the unexplored areas of the personality or psyche that can still influence behavior. As is the case with everyone, there will always be aspects of a person’s life that are easier to explore and expose than others. Our level of comfort with vulnerability is shaped by the communities in which we were raised. If you are anything like me, many of your earliest memories include endless instruction about what is socially (un)acceptable and (in)appropriate to disclose, to which audience, and in what setting! Take a moment however, to deflate your defenses. Allow yourself to begin dropping down toward the doorway to the deep. You may find, as I have, solace in the sinking.

Q & A:

- a) Who were the most important figures in your infancy, childhood and/or adolescence?
- b) What role did they play?
- c) Create a genogram⁴ noting the strength/weakness of relational bonds in your family. You can locate a myriad of wonderful examples on the following website:

<http://templatelab.com/genogram-templates-symbols/>

⁴ Genograms are family maps that can highlight historical and current patterns in interpersonal relationships and major events.

- d) Did you discover any trends in your family history? Note: This is not relegated to medical history. It can include interpersonal, spiritual, professional, psychological, emotional, even addictive patterns.
- e) Create a time line from ages 0-12 years old. Draw it horizontally and record all experiences you consider to be positive above the line and all experiences you consider to be negative below.
- f) What, if anything, did you discover about your childhood from this timeline?

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Chapter Two:

A Color Palette Containing Faith, Fear, and Fractals

“Color is a power which directly influences the soul. Color is the keyboard, the eyes are the hammers, the soul is the piano with many strings. The artist is the hand which plays, touching one key or another, to cause vibrations in the soul.” – Wassily Kandinsky

It was devastating to watch my mother pace from the front door to the back door attempting to block Bobby’s exit from the house and our life. Her tears and frenetic pleas for him to stay were frightening. The house was a dingy, mustard yellow. I recall that clearly. The color representative of decay and caution—if only the warning had been heeded. The house was old and ominous, and I was young and innocent, and no match for the growing darkness within its walls. That was when the roller coaster dream first seeped through my subconscious and began to haunt my sleep.

But scenes such as these were not uncommon. Having left Texas and my father behind, my mother relocated from Houston to the small town of Crowley, Louisiana where I was born. My grandparents were pastoring a church in Crowley at that time. While working as a secretary at the local police department, my mom met and married a retired police officer named Bobby. To this day, I cannot recall encountering a more abusive man. And that is saying a lot as I have worked as a therapist in a domestic violence shelter and a transitional living facility for battered woman and children since becoming a clinician. He was psychologically, physically, emotionally, and sexually abusive to all of us—mom, Leilani, and me. This was a pattern for Bobby whose own biological children and former wife also suffered through years of abuse.

Because of his background as police officer, his power over us was even more complete. There was no help. Understandably, but unfortunately, none of his former colleagues wanted to intervene. He been involved in a work-related accident many years prior and left the police force prematurely, medically disabled. However, that did not change his behavior as he continued to perpetrate and perpetuate those same abusive patterns in all of his intimate relationships.

That night, the scene was set. It was yet another horrifying re-run that played endlessly throughout their five-year relationship. Frozen, I watched as he lashed out, verbally berating, and manipulating my mother—the strongest woman I knew. Too terrified to look away, I watched her transform before my very eyes. She became feeble and frantic, begging for him to stay. Finally, feeling unheard and unable to communicate her “love” for him, mom punched the glass in the front window of the house. It shattered explosively. In the deafening silence that followed, I recall the sweet smell of honeysuckle that was growing outside the window drift into the stifling room. Then came the color red, running in rivulets down her arm, dripping onto the wood floors. Red, the color so often associated with danger, warning, passion, or love.

“Stop! Please stop!” Leilani and I were crying now, begging for them to stop fighting, for the violence to end, and someone to let us go; pleading for the proverbial stoplight to turn green. According to an ever-expanding art therapy community on the topic of color psychology, green tends to have a strong emotional correspondence with harmony, tranquility, has great healing power, and suggests stability and endurance. Green, as opposed to red, often correlates to safety; it is the color indicative of free passage in traffic (Seamark, 2008). Perhaps that is why it has always been my favorite color. I desperately wanted to escape the painful picture that was my life disintegrating right before my very eyes.

Bobby was happy now, satisfied with her reaction and satiated by ours. His eyes twinkled maliciously and he smirked. Wiping the sweat and spit which had lathered to a foam around his mouth, he announced that he would stay. The abusive cycle was now complete. The tidal wave of emotion began to recede, and the demons shrank back into the darkness. But for how long? How long could we maintain? How long would life remain green before it returned to sickly yellow and eventually, and inevitably, dangerous red?

This and other similar scenarios played out ad nauseam throughout my childhood from ages two to seven. But like many, if not most abusive homes, this was kept quiet and confidential. Outbursts involving broken windows could always be explained away to my mother's clumsiness. Few people knew of the violence, and even fewer cared to get involved. Of those who tried, my mom's family was primary. Most specifically my grandparents, William and Georgia Mae, and mom's sister, Lois, and her husband Dennis. While family members can extend only limited support to someone in an abusive relationship due to the strained and estranged dynamics that occur, one of the unique ways in which my family offered aid was religious and spiritual in nature.

As I mentioned previously, my grandfather was a pastor. I was born in Crowley, LA only because he and my grandmother were overseeing the Bible Missionary Church in that area at the time. Mom moved there to be close to them. Their faith in God was the one constant I can recall in the chaos. It added many other colors to my life, and in a world that was becoming nothing more than yellow and red, they were welcome additions.

First and foremost, their collective influences brought the color blue—the color of the sky and sea. Often it is associated with truth, depth, stability, loyalty, wisdom, intelligence, faith, and

heaven (Seamark, 2008). And because my immediate family lived in hell, my grandparents' home felt like heaven. It was full of peace and reprieve from the pain.

From their faith, my own began to develop. I learned that the Western Judeo-Christian faith contains the concept of "the second coming of Christ." This phenomenon is described as the point in time when Jesus will return for the "church." This entity is comprised of a body of people who believe that Jesus Christ is the only Son of the one true God, Creator of the Universe, and everything therein. They maintain that He died for the sin of all humanity, and that He is the only way to a restored relationship with a Holy God through the acceptance of His leadership and lordship in their everyday lives. Biblically, the time of the second coming is unknown to everyone including Jesus, only God the Father knows the day and the hour of Christ's return (Matthew 24:36, New International Version). This event will culminate in the retrieval of Christians (Christ followers) from the world and even from the dead, and will mark their mass exodus to Heaven, a place prepared for those who have accepted Christ as Savior. It is described extensively in the following passages:

...he will swallow up death forever. The Sovereign Lord will wipe away the tears from all faces; he will remove his people's disgrace from all the earth. The Lord has spoken. In that day they will say, 'Surely this is our God; we trusted in him, and he saved us. This is the Lord, we trusted in him; let us rejoice and be glad in his salvation.' (Isaiah 25:8 – 9, New International Version)

My Father's house has many rooms; if that were not so, would I have told you that I am going there to prepare a place for you? And if I go to prepare a place for you, I will come back and take you to be with me that you also may be where I am. You know the way to where I am going. (John 14:2 – 3, New International Version)

He will wipe away every tear from their eyes. There will be no more death or mourning or crying or pain, for the old order of things has passed away. He who was seated on the throne said, 'I am making everything new!' Then he said, 'Write this down, for these words are trustworthy and true.' He said to me: 'It is done. I am the Alpha and Omega, the Beginning and the End. To the thirsty I will give water without cost from the spring of the water of life. Those who are victorious will inherit all this, and I will be their God and they will be my children.' (Revelations 21:4 – 7, New International Version)

The primary theological focus of the Bible Missionary Church was on Heaven and life lived in preparation for a future home with no more suffering. While these beliefs lent themselves quite naturally to a sincere and earnest desire to escape my difficult circumstances, they did not dictate how faith is expressed in the face of fear and unrelenting, inexplicable pain and abuse.

Enter the colors black and white. White's associations can include light, power, goodness, elegance, innocence, purity, neutrality, and virginity (Seamark, 2008). It is the consummate color, and considered by some to be the color of perfection. That was the answer that was proposed to the congregants: perfection. That's how you attained the attention and intervention of the divine. After salvation you, you sought sanctification. This second "act of grace" is based upon the work of the theologian John Wesley. While sanctification can be instantaneous, it can also be a gradual process. This belief eventually gave rise to the Holiness movement in the 1860s. Intrinsic within the Holiness movement is a second work of grace, which is a cleaning from the compulsory committal of sinful behavior. This is an experience described as entire sanctification, which leads to Christian perfection (Jones, 1974).

This belief system has some Biblical merit, and in no way do I discredit the heart behind it. Unfortunately, this black and white approach provided little to no context for any life lived

outside of the congregants' shared, sheltered experience. There was little-to-no indication of their ability to fully comprehend or empathize with our situation and set of circumstances. While well-meaning, it was inflexible and unyielding, bordering on unmerciful, albeit stemming from both good intentions and a general lack of understanding.

Nevertheless, I believe lack of context or the ability to compromise is the quintessential allure of any religion built upon performance and perfectionism. If rigidity is anything, it is clear-cut and consistent. And as I longed for consistency more than anything else, I was drawn like a moth to a flame. Combining the fear of standing out at all in my abusive home (negatively or positively) with the fear of the divine and doing wrong, I became highly perfectionistic and performance-oriented. I sought to be good enough to escape the wrath of both God and man by "going to the altar" every Sunday in church and seeking salvation and sanctification. The depth of my prayers depended upon my perceived level of depravity that week as a five-to-seven-year-old child! Whether wrong or right, black or white, the experiences I had within that church, and as a result of family, inexorably shaped me and my perception of and relationship with and to God. Ultimately, it set the stage for the dramatic interplay between spirituality and health that would occur in the coming years.

By the time I was seven, my mother, sister, and I had been separated from and reunited with Bobby more times than I can recall; and they were even married and divorced twice before it was all said and done. In fact, it ended abruptly and unexpectedly. Mom picked Leilani and me up from school one day in Crowley when I was in the second grade, with one change of clothes apiece, and told us we were leaving town. We stayed with various acquaintances and in two shelters, one in Baton Rouge and another around New Orleans before mom made the decision to relocate us to Illinois, over a thousand miles away, where her two older brothers lived.

In the meantime, Bobby searched frantically for us. After we arrived safely in Illinois in March 1990, he placed the call to my uncle's home where we were staying and informed us that he knew exactly where we were. It was an intimidation tactic, nothing more, but I'd be lying if I said the three of us didn't feel like Julia Roberts in *Sleeping with the Enemy* when her ex locates her after her daring escape. Gratefully we would never see him in person again before he died of AIDS in 1994. However, it would be many, many more years before we learned not just how to survive, but how to live.

My time in Illinois spanned ages eight to twelve. It was while we lived there in 1993 that my little sister was born, and I began my very first menstrual cycle at age eleven. Apparently, it was important enough to elicit my inaugural journal entry in my bright Lisa Frank diary which was splattered with every vibrant and psychedelic color that the early nineties could muster. Finally I joined the ranks of all my other female forebears who had already pioneered this path for me.

The following spring in 1994, my mother decided that her growing family of then three daughters would again relocate, this time back to Houston. Like the move to Crowley in 1982, this move was based upon many factors—the primary of which was the fact that my grandparents were again pastoring a church nearby. Consequently, my teenage years were spent in Houston, living near my grandparents, aunt, and uncle. This move also brought with it the exploration of God in a whole new way, through attendance at Lakewood Church and exposure to the spiritual leadership of Pastor John Osteen. For the first time, I began to develop an understanding of God not merely as a figure who demanded perfection, but as a Father who enjoyed my company.

During this time, my writing began to flourish. I penned songs and poems inspired by this new and revolutionary concept of Christ as kind and caring. There I learned that He had good things in store for me.

‘For I know the plans I have for you,’ says the Lord. ‘They are plans for good and not for disaster, to give you a future and a hope. In those days when you pray, I will listen. If you look for me wholeheartedly, you will find me. I will be found by you,’ says the Lord. ‘I will end your captivity and restore your fortunes. I will gather you out of the nations where I sent you and will bring you home again to your own land.’ (Jeremiah 29: 11 – 13, New International Version)

I also began to learn about the concept of healing and how it applies to current-day Christians and the world at large. In fact, while attending a youth service one Sunday evening as a teenager, I was completely healed of severe asthma. I believe that this cure was miraculous because after that night I never had to take medication again. Completely amazed by this manifestation, I took my newfound freedom and faith with me everywhere and began praying for the sick. This is a Biblical practice outlined in the book of Mark 16:17 – 18. Through prayer and intercession, I saw others healed of minor medical conditions such as headaches and major disabilities such as blindness.

Of these “miraculous events,” praying for my high school classmate’s severe gynecological issues was among the most challenging to understand in the years ahead when my own worsening gynecological issues were not improving with prayer. Often I would mentally replay her excited account of how the pain immediately left her body as I prayed for her. To this day, I still firmly believe that healing is possible through the completed work of Christ on the cross (Isaiah 53:5). Unfortunately, the lack of contextualization for those who are not healed

pervades even less rigid communities of faith. Many times, a person's persistent illness is attributed to a) the presence of sin in someone's life that may be preventing divine intervention, b) a lack of faith in God to bring about healing, c) demonic obstruction of the divine. The common denominator in all three is *you*. The underlying message is that if *you* do enough, believe enough, pray enough, and become good enough, there is no reason why *you* shouldn't be completely healed. While many of these theological points of view are based upon letters written in red—the Biblical words of Christ—the beliefs are steeped in black and white. All or nothing. Painfully, there is no room for grey on the Christian color wheel I grew up with. Gray is neutral and controlled, often inconspicuous. It is considered a color of compromise. Perhaps that is because it sits between the extremes of black and white (Seamark, 2008). What happens however, when your lot in life falls outside these parameters? How do you live in a world of gray? What do you do when you do when you are not healed? When you do not get better? Or when circumstances do not improve despite prayer and intercession? These questions were becoming particularly pertinent as my health became increasingly tenuous and unpredictable.

It would be many more years before I had to answer that question—fourteen to be exact. By then I was twenty-six years old and living in Tulsa. Upon completion of high school in 2000, I was awarded a tuition scholarship to attend Oral Roberts University. I left Houston at seventeen to embark upon my undergraduate journey. In 2004 I completed my bachelor's degree in theology and went on to pursue a master's degree in counseling, with an emphasis in marriage and family therapy. After graduation in 2007, I entered the field of counseling and had begun to diligently examine and systematically deconstruct my own theology and ideologies about myself, others, and the world around me.

Fundamentally, theology asks this question: “*Is it true?*” Whereas counseling psychology wants to know, “*Is it helpful?*” The combination of the two shattered my schemas almost as explosively as the front window of my dingy yellow childhood home had been shattered by my mother in a moment of desperation. It was at this juncture that I stumbled upon a program airing on PBS late one evening, and first encountered the concept of fractals. Disclaimer: I do not claim to be a mathematician or physicist or anything remotely related to either. However, if following Bill Nye the Science Guy on Twitter counts for anything, then my credibility is solid! According to Jonathan Wolfe and his colleagues (2014),

Fractals are infinitely complex patterns that are self-similar across different scales. They are created by repeating a simple process over and over in an ongoing feedback loop.

Driven by recursion, fractals are images of dynamic systems – the pictures of Chaos.

Geometrically, they exist in between our familiar dimensions. Fractal patterns are extremely familiar, since nature is full of fractals. For instance: trees, rivers, coastlines, mountains, clouds, seashells, hurricanes, etc.

Intrinsically beautiful, these mathematical dimensions are all around us. They are all-color inclusive.

It was while watching this program that I began to conceptualize the emerging patterns in my life born out of pain and disaster, as both beautiful and breathtaking. In the same way that the concept of fractals was derived from chaos theory, perhaps there was purpose in the pandemonium—both the immediate medical symptoms associated with the then-undiagnosed endometriosis, and the historical and psychological pain arising from years of abuse. Maybe something in my past, present, or future was salvageable. Could it be that my definitions of *both* “good” and “bad” were mostly human constructions and merely partial replications of truth?

Reflections interpreted from shattered and darkened glass? (I Corinthians 13:12) Rainer Maria Rilke captures this in his poem entitled "You, neighbor god."

You, neighbor god, if sometimes in the night
I rouse you with loud knocking, I do so
only because I seldom hear you breathe
and know: you are alone.
And should you need a drink, no one is there
to reach it to you, groping in the dark.
Always I hearken. Give but a small sign.
I am quite near.

Between us there is but a narrow wall,
and by sheer chance; for it would take
merely a call from your lips or from mine
to break it down,
and that without a sound.

The wall is builded of your images.

They stand before you hiding you like names.
And when the light within me blazes high
that in my inmost soul I know you by,
the radiance is squandered on their frames.

And then my senses, which too soon grow lame,
exiled from you, must go their homeless ways.

Suddenly I was standing at a crossroads experiencing a crisis of fear, faith, and fractals.

Would I ever be able to synthesize my conflicting beliefs about God with my wildly diverse experiences of the world? Within me a war raged, steeped in colors of confusion. The color wheel was spinning out of control. All I knew for certain is that the words of T.S. Elliot rang repeatedly throughout my mind, "For last year's words belong to last year's language, and next year's words await another voice. And to make an end is to make a beginning."

~ Psychological Insights & Therapeutic Thoughts ~

Making Meaning of the Mess

In the psychological community, there is a growing body of research investigating the impact of “religion and spirituality” upon physical and mental health. It is a topic of increasing interest and publication. While my research is by no means exhaustive, I continue to encounter many psychological articles and journals combining the two terms “religion and spirituality.” For this reason, although the two are often thought of as quite distinct, the term *spirituality* will often be interchangeable with the term *religion* in this text. When in fact, the two are quite different. Generally speaking, members of an “organized religion” in the Abrahamic traditions place value on shared beliefs and practices and the ritualistic observance of faith in a transcendent in the context of community. On the other hand, a spiritual person views the spirit as the center of moral and religious nature, feeling a connection to the transcendent being from both without and within (Koenig, King, & Carson, 2012). So, while a religious person can be spiritual and a spiritual person can be religious, recognizing and honoring those distinctions is important. As is the disclaimer that I will be moving back and forth between the two terms in the text!

Historically, many of the treatment interventions implemented in medical and mental healthcare in both eastern and western cultures originated within religious and spiritual communities. In fact, many of the first hospitals established in the United States were built by various religious organizations and often staffed by religious orders (Koenig, 2012). The commonality of physicians as clergy lasted from the Middle Ages all the way through the French Revolution. In this way, many of the clergy in the early American colonies were able to subsidize their meager salaries from their respective religious communities.

This same precedent was set in the field of mental health. “Care for those with mental health problems in the West also had its roots within monasteries and religious communities” (Koenig, 2012). To illustrate, the concept of “moral treatment” arose from the Quaker community in England, where they established the York Retreat. Eventually they brought this modality to United States where it became the predominant form of psychiatric treatment. The Quakers even established the very first private U.S. institution dedicated solely to the treatment of the mentally ill. It was called Friends Hospital or Friends Asylum and was founded in Philadelphia in 1813. Other hospitals that followed in their footsteps included

McLean Hospital (established in 1818 in Boston, and now associated with Harvard), the Bloomingdale Asylum (established in 1821 in New York), and the Hartford Retreat (established in 1824 in Connecticut)—all modeled after the York Retreat and implementing moral treatment as the dominant therapy (Koenig, 2012).

Unfortunately, while religious institutions often led the way in offering compassionate care to the mentally ill, they were also responsible for persecuting them for hundreds of years (Koenig & Larson, 2001).

The complete separation of religion and spirituality (R/S) from the field of psychiatry occurred mainly as a result of the work of Sigmund Freud, often called the Father of Psychoanalysis. Freud encouraged the separation of R/S from psychiatry after being introduced to the famous French neurologist Jean Charcot in the mid-1880s. Charcot exposed Freud to the neurotic and hysterical aspects of religion. This interaction profoundly influenced Freud for he would go on to write *Religious Acts and Obsessive Practices* in 1907, *Future of an Illusion* in 1927, and *Moses and Monotheism* in 1939. Despite their different themes, one common thread runs throughout all three: R/S as a cause of hysteria and a contributor to unstable mental health.

The beliefs and practices associated with R/S have been attributed to underlying pathology since that time. Inaccurate religious images and related diagnoses have pervaded the psychiatric world and the Diagnostic and Statistical Manual III / III-R⁵ (DSM III and DSM III-R) (Post, 1992; Richardson, 1992; Verghese, 2008).

Enter the age of psychoanalytic psychotherapy. It was a time filled with all things weird and wonderful: couches, distant clinicians, psychosexual stages of development, and the rise in popularity of psychotropic medications. Each contribution was an important step in the evolution of the field of mental health in the United States, and the work of many of these clinicians' still enjoys a degree of respect to this day. However, like almost any other field, mental health is dynamic and constantly changing. Soon it became evident that focus a presumed "female hysteria" or and "Oedipal complex" would not lead to lasting, positive psychological change. Consequently, clinicians of all licensure levels began to delve deeper into the belief systems that seemed to perpetuate unhealthy patterns of behavior in their patients.

As a result of their work, many clinicians now maintain that the R/S cannot be separated from psychiatry/psychology. They may be inextricably linked. Outcomes of a recent research study conducted by the University of Maryland Medical Center indicate that "spiritual practices tend to improve coping skills and social support, foster feelings of optimism and hope, promote healthy behavior, reduce feelings of depression and anxiety, and encourage a sense of relaxation" (Ehrlich, 2015). This is only one example of a growing body of research demonstrating the benefit potential, and ultimately answering the question of helpfulness with regard to the impact of R/S on mental health. But what of unhealthy belief systems that may limit growth and

⁵ <https://www.psychiatry.org/psychiatrists/practice/dsm/history-of-the-dsm>

change? Could Freud, the Father of Psychoanalysis, be correct in theorizing that R/S often served to hinder and destabilize the mental health of patients?

Because my academic background is both theological and psychological, I have a deep appreciation for the work of American psychologist, Albert Ellis. He is the originator and mastermind behind the therapeutic theory and intervention called Rational Emotive Behavior Therapy (REBT), formerly known as Rational Therapy (RT) and Rational Emotive Therapy (RET). This theory was devised in 1955 and rose to preeminence in a time when psychoanalysis reigned supreme. Ellis eventually broke with psychoanalytic ideologies in theory and practice, and began calling himself a rational therapist. He developed RT in an effort to facilitate a more active and directive form of psychotherapy.

A rational therapist seeks to help clients uncover the ways in which their personal beliefs may be causing emotional pain. This approach involves active client engagement in challenging and changing these self-defeating beliefs by demonstrating their rigidity and irrationality. Ultimately, Ellis maintained that through RT and cognitive reconstruction, clients would be capable of understanding their self-defeating behaviors in light of their core irrational beliefs and then of developing more rational constructs (McGinn, 1997).

As you may recall, the fundamental question of the study of theology is this: *“Is it true?”* While those within the field of counseling psychology are concerned with one thing—*“Is it helpful?”* Ellis’ body of work on REBT includes the following grid which is a useful synthesis of these two trains of thought.

Table IV

	<i>TRUE</i>	<i>UNTRUE</i>
<i>HELPLFUL</i>		
<i>UNHELPLFUL</i>		

This tool or construct is helpful when addressing the underlying belief systems that cause unhelpful outcomes. To clarify, the following is an example of a case I encountered while working as an elementary school-based therapist in a low-income, high risk community. My client was a nine-year-old boy who originally began seeing me for ADHD management. His mother was only marginally involved in his life due to her own significant issues of substance abuse and trauma. Due to child protective services' involvement, my client lived with his paternal grandparents, despite his father's albeit minimal interactions with him.

During his time as my client, his mother left a local bar with her friend and an unidentified male one Friday evening. The next morning, her body, and that of her friend, were discovered dumped off the side of the highway wrapped in a plastic tarp. Following an investigation, it was determined that she and her friend were raped, possibly tortured, and then killed by this man, and their bodies disposed of thereafter. Needless to say, my client was destroyed.

In an effort to alleviate the suffering he was enduring, I used this grid to help him not only discover what was true and untrue about the horrific situation, but also what would facilitate healing and foster hope. Was it true that his mother probably suffered? Yes. Was it true that my client as a nine-year-old boy was helpless to save her? Yes. Was it helpful to think and ruminate about it? No. So, we explored his beliefs about his responsibility to save his mother, as well as the idea of life after death. He firmly believed that she was in Heaven and with him

simultaneously. As such, that became the focus of treatment—her newfound peace and the fact that she was no longer in pain—both understood by the patient as true *and* helpful.

That is the crux of this section of the chapter. My purpose in the inclusion of this topic is to suggest that our beliefs about or engagement with R/S may impact medical and behavioral outcomes. C.L. Parks and his colleagues (2017) propose that

Recognizing and understanding the potentially powerful roles that religiousness and spirituality (RS) may serve in the prevention and amelioration of disease, as well as symptom management and health related quality of life, significantly enhances research and clinical efforts across many areas of behavioral medicine (p. 39).

Furthermore, in an article entitled, “Religion and Public Health at Harvard,” Tyler J. VanderWeele, PhD and Harold G. Koenig, MD describe a course taught by VanderWeele in Harvard’s School of Public Health. The content was based, in part, upon Koenig’s book *Handbook of Religion and Health*. Due to a growing body of rigorous research suggesting that connection to religion improves both medical conditions and mental health, and due also to a rapid incorporation of courses on spirituality and health in medical school curricula over the past twenty years, VanderWeele and Koenig propose that to neglect R/S in “discussions of public health and social determinants of health is to miss an important aspect of life that appears to confer substantial health to large portions of the world’s populations” (p. 47). Interestingly, the DSM III-R, rife with anti-religious themes, was replaced by the publication of the DSM IV in 1994. The removal of these images and related diagnoses by the American Psychiatric Association (APA) may account, in part, for the revival of interest in spirituality and health over the past two decades in the psychiatric professions. Studies assessing the relation between spirituality and quality of life, even studies with poor correlations such as that conducted by

João P. Da Silva and Anabela M. S. Pereira (2017), continue to suggest that the spiritual outlook of the patient is important, especially when designing and implementing psychological interventions.

Research on the interplay of R/S and good outcomes in the treatment of medical and behavioral conditions is ongoing. In fact, it was while reading one of three feature articles in a magazine entitled, *Spirituality and Health*, that the title and concept for this book began to emerge. However, if religious or spiritual beliefs are producing stagnation in any area of life, then they are no longer beneficial and must be re-examined for both “truth” and “helpfulness.”

Fair warning: this can be an exceptionally anxiety-provoking process. Frantz Fanon, Afro-Caribbean psychiatrist, philosopher, revolutionary, and writer had the following to say about it in his book *Black Skin, White Masks*,

Sometimes people hold a core belief that is very strong. When they are presented with evidence that works against that belief, the new evidence cannot be accepted. It would create a feeling that is extremely uncomfortable, called cognitive dissonance. And because it is so important to protect the core belief, they will rationalize, ignore and even deny anything that doesn't fit in with the core belief (1952).

Cross-examination of your core beliefs is daunting. In the same way that a child would rather have a parent with poor parenting skills than no parent at all, the desire to cling to beliefs, no matter how unhealthy, is incredibly strong. To illustrate this point, I once had a graduate professor give the following example of how untrue or partially true beliefs can cause significant emotional distress. He described a counseling session in which a young woman from a religious background was verbally chastising herself for her way of doing things and being human. She conceptualized God as being very displeased with her. In fact, she had become so emotionally

compromised and depressed, that she was contemplating suicide. As she wept, my professor interjected, “Perhaps instead of killing yourself, you need to kill your god.” While sounding sacrilegious initially, it was the catalyst she needed to begin crafting a new cognitive construct. It effectively shattered the rigidity surround her R/S and created the space and potential for her to develop a new and more flexible system of belief.

This is known as transformational change. Change of this magnitude is capable of creating hope. But according to Proverbs 13:12a, “Hope deferred makes the heart sick,” and as my health continued to decline with no solution in sight, I found I could no longer reconcile the kaleidoscope of Christianity I witnessed in the various churches I attended throughout my life. While I deeply love and respect many of the religious practices and people within these denominations, certain aspects, characteristics, or “colors,” if you will, were over-emphasized while others were neglected entirely. Often the theology seemed frail and fragile, breaking easily under the weight of my history of childhood abuse, life’s day-to-day disappointments, and a growing number of inexplicable medical symptoms. However, after diligent theological and psychological search, study, and deconstruction, my personal perception is that the Holy Trinity consisting of God the Father, God the Son, and God the Holy Spirit cannot be contained in a single, solitary color or even a subset of colors. Rather, together they are the consummate color wheel, including every shade and hue, radiating light and life (Psalm 36:9, New International Version).

This paradigm shift would become even more important to me as I approached a time of growing darkness in my life. My health was failing and there was no diagnosis, no definitive answers, only prescription after prescription to manage the symptoms. My faith was faltering, fear growing, and fractals emerging.

Q & A:

The following is a list of fill in the blank questions. My purpose for their inclusion is to facilitate introspection into your core beliefs and psychological schemas about R/S, yourself, and your relation to the world. Write the first thing that comes to your mind. Try not to change or judge your response no matter how “good” or “bad” it appears to be. The rationale behind this exercise is that core beliefs most often reveal themselves in the form of automatic thoughts.

- a) God is _____
- b) Religion is _____
- c) Spirituality is _____
- d) People are _____
- e) Men are _____
- f) Woman are _____
- g) The world is _____
- h) I am _____
- i) Bad things sometimes happen to good people—T/F? Why or why not?

Did any of your answers surprise you? If yes, in what way?

Do you believe that any of your answers may somehow be untrue or unhelpful?

If yes, how will you begin working to change and transform these beliefs into something true and helpful?

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Part 2: Mid

Chapter Three: Hard Pill to Swallow

CHAPTER ONE

What It Really Means to Have Endometriosis

From a medical point of view, endometriosis is defined as a disease whereby the inside lining of the uterus, the endometrium, somehow implants and grows outside the uterus. Endometriosis lesions, which are like blisters, can be found anywhere in the pelvic cavity, including in all the reproductive organs, the bladder, bowel, intestines, colon, appendix, and rectum. Endometriosis can also cause scar tissue (adhesions), which can make internal tissues sticky and sometimes even cause internal organs to fuse together. The hallmark of endometriosis is severe pain. It can also cause infertility.

So much for the medical definition of endometriosis. In my experience treating women with pelvic pain—more than 25 years of residency, private practice, and fellowship—the medical definition doesn't even come close to describing what it's like to experience this disease.

Having endometriosis is like having tens or hundreds of excruciatingly painful blisters or bee stings covering the inside of your pelvis. We all know how painful a small blister on the foot can be, and how sore the surrounding tissue is. When you're hiking with a blister on your heel, every step can cause a sharp pain. A blister on your hand from a cooking burn can bother you for weeks, every time you accidentally touch it. Now imagine those blisters multiplied and multiplied, spread throughout your internal organs; picture the entire pelvic area red, raw, and sore. When the blisters ooze, they can spread to form other blisters, like poison oak does. Any jostling or movement aggravates the pain.

Image courtesy of <https://www.pinterest.com/pin/25966135328518621/>

November 7, 2009:

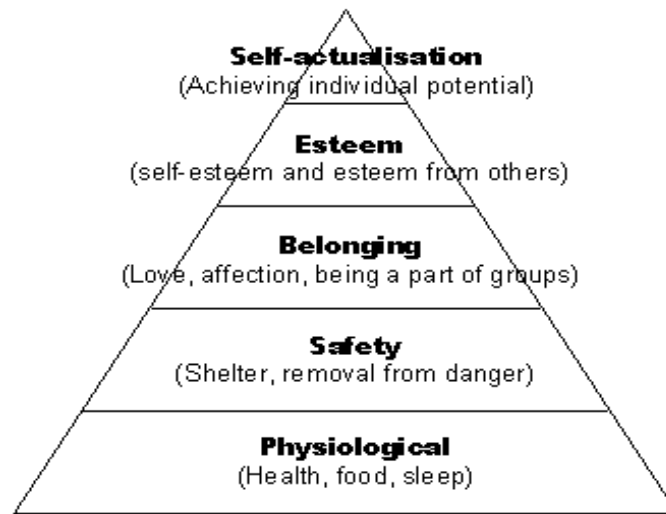
Yesterday my roommate Yoli shared a dream she had about me. We were returning to the 1950s brick house we were renting in east Tulsa after taking full advantage of Sonic's happy hour. Barely able to hold onto our oversized Styrofoam cups, we sloshed up to the curb when she looked over and blurted out:

"You and I were standing on the platform of this old-school wooden roller coaster. You were an adult in the dream, but you were describing some of the challenges of your childhood to me, including all of this *pain* and *difficulty* you experienced." She then became animated, gesturing with her arms to accurately describe what she saw. "As you were talking, I watched little Carma, just a passenger on this *crazy* roller coaster, drop *again* and *again* into oblivion! But get this! *This* ride *also* had *loops* and *cork-screws*! It was flyin' around *everywhere*! So, when the car finally flew past us on the platform, I was shocked by what I saw...

"Little Carma was just sitting there, inside the roller coaster car, playing with her dolls. Like, totally and completely at peace!" She laughed and hesitated only a moment before adding, "You know, as crazy ridiculous as that dream was, I feel like it might actually apply to this time of your life as well. Like, everything *feels* like it is going *crazy* and spinning out of *control*, but you have that same peace, Carma."

To this day I can recall sitting there in shock, holding back tears. There was only one other person in the world who knew about that dream, and it wasn't Yoli. Growing up in the chaos and trauma of my childhood, I didn't have time to address the internal turmoil that arose from those experiences. As Abraham Maslow's Hierarchy of Needs (1948) image outlines here, I was so busy staying afloat that I never dealt with the deep questions lying beneath the surface.

Table V



When I finally left home, I found I could no longer shore up or shove down the painful memories. They came floating, sometimes fighting, to the surface of my mind. With the memories came the questions. One in particular cried out louder than the rest, and it ran on repeat throughout my tormented mind. “Why didn’t You (God) make it stop?” Despite the fact that Yoli’s dream was not a direct answer to that question, it pacified me. For to me it meant that while God may not have removed all of my suffering, He had given me the peace I needed to make it through my past, and sustain me in the present. And the timing could not have been better for this revelation, because it was in 2009 that my health suddenly took a turn for the worse.

I had always experienced an inordinate amount of pain with monthly cycles while growing up. I can recall bleeding for up to fourteen days out of the month. Some days I would become incapacitated and would have to sit or lie down until the pain passed. These episodes could last anywhere from a few moments to several days. However, I was not throwing up or blacking out like my mother, aunt, and sister were, so I thought I was doing well. And with my

family history, I felt as though my pain severity was relatively normal and part of the process of womanhood.

I grew up in a church that placed a premium on sexual purity. Influenced by a very conservative Christian upbringing, I had remained a virgin. Unfortunately, the subset of Christianity to which I was exposed included the thought process that if you are not sexually active, there is no need for gynecological care until right before the wedding. To clarify, this level of ignorance toward women's sexual health and wellness may be construed as misogynistic, and may *not* be embraced by the wider Christian movement. However, it certainly impacted my family starting with my aunt and my mom.

Mom attempted to change that with me, going as far as making an appointment for me with an OBGYN when I was seventeen, before I left home for college. However, the day of the appointment, I started my monthly menstrual cycle, and the appointment was canceled. Perhaps because of that old mindset, or the busyness of life, or because I minimized my symptoms in comparison to theirs, it would be nine years before I rescheduled. By then, my symptoms were unmanageable. While routine gynecological exams and Pap smears would not have detected what was ailing me, the family history of endometriosis would have alerted most doctors to monitor me for the disease.

By the time I turned twenty-five it was evident that the increasing symptoms were more than monthly flare-ups. I was also experiencing monthly yeast infections, and spotting a week before and a week after my cycle. Three weeks out of every month were spent in pain and discomfort. And as the symptoms increased, every day out of every month was spent with a growing uneasiness that something was really wrong with me despite my continual confession that "endometriosis stopped with me!"

In 2009, at twenty-six years old, with symptoms steadily worsening, I finally made an appointment to see a gynecologist. After explaining my medical presentation to the doctor, she recommended starting me on a very low dose of a birth control known as Lo Loestrin Fe as I had never taken one before. Happy to try and manage the pain in whatever way possible at that point, I began using my very first monthly blister pill pack. Unfortunately, I discovered by month two that this medication would not work. This would be the first of many, many unsuccessful attempts at using birth control to regulate my bleeding. In the meantime, my Pap smear came back clear.

Between months two and three on the birth control, I developed two full cycles per month. I timidly called the OBGYN and left a message that was something to the effect of, “I’m no doctor, but this *could* be considered a step backward.” I received no response. So, I placed several more calls with the same outcome before resorting to a new gynecologist.

This new doctor switched me to a new birth control called Yaz. It was presented to me as a stronger and more aggressive approach to managing the increasing pain and symptomatology associated with periods. When I inquired about my reaction to Lo Loestrin Fe, it was dismissed as a dosage issue, which had been too low to make a difference for me. Again, a Pap smear was performed, and I was handed a prescription for birth control.

The effectiveness with this birth control (as defined or evidenced by alleviation of pain and persistent bleeding) lasted between two and three months before the pain and excessive bleeding returned with a vengeance. I was spiraling downward. Symptoms were not returning to baseline after these medication trials. They were coming back with increasing severity. Growing uneasiness turned to fear.

At twenty-seven, I moved across town to live on my own, and therefore required cheaper rent. While I had obtained my master's degree in 2007, I would spend the next three years fulfilling supervision stipulations and direct service hourly requirements set forth by the Oklahoma state board of licensed marriage and family therapists (LMFT). I was working three jobs to support myself under a Board Approved LMFT Supervisor who ensured that my clinical work was exemplary and meeting both state and national standards of care. Needless to say, an efficiency for \$399 per month was an offer I couldn't refuse!

This move precipitated yet another OBGYN, as my former doctor was now too far away, and Yaz was yielding similar lackluster results. I had remained guardedly optimistic, but my optimism was waning and my guard slipping. Dread was beginning to find its way behind the façade and to torment me with memories of the fertility issues plaguing my family. I carried this weight with me into the doctor's office that day. Her bedside manner did nothing to alleviate the anxiety. Although she was the first OBGYN to show interest in my family history of endometriosis and infertility, she was the least caring.

After performing the "standard pap smear," she sat down in a chair, allowing me time to awkwardly compose myself on the exam table before Q & A. As I prepared to rattle off the spiel I had mentally rehearsed about my family history of endometriosis, I suddenly found myself fighting back tears. Confused and a little embarrassed, I tried to act nonchalant as I recounted the various gynecological and fertility issues faced by the women in my family. From my perch on the exam table, I looked down at her hopefully. She responded,

"Weeeeelll, if I go in there surgically and discover you have endometriosis, then I will have to laser you off and put you on medication that will throw you into menopause prematurely." Then nothing. Just silence. She stared up at me expectantly, eyebrows raised in

feigned interest, head cocked to the side. My mouth went dry and my mind went blank. I recall sitting there in my hospital gown, the exam table paper sticking uncomfortably to my naked lower half, facing her and the three medical students who were shadowing her that day. Was there a question, I wondered frantically? I didn't know what she meant, much less how to respond. And if I wasn't scared before, I definitely was then. I simply froze. All I could do was focus on the dust motes dancing softly in the sunlight above her mouse-brown hair that was twisted into a clip at the back of her head. At some point I reached the conclusion that she wasn't going to help me. Perhaps no one would help me. For the first time, fear turned to anger.

Finally, I stammered something about not wanting to be in menopause, to which she heartily agreed, and recommended another birth control. This one was purely progesterone. I took the prescription, and left convinced of two things: 1) there was *definitely* something wrong with me that doctors were not taking the time to examine, diagnose, and treat, and 2) this medication was *not* going to be a good fit for me. In both cases, I had nothing more to go on than my intuition and previous experience with medications. As it turns out, I was right on both counts. What I did *not* know was that there are many, many things wrong with the ways in which women with endometriosis are diagnosed and treated.

In fact, Cox, Henderson, Anderson, Cagliarini, and Ski (2003) conducted a series of focus groups based out of Epworth Hospital in Melbourne, Australia to determine the types of issues women face when dealing with endometriosis and laparoscopic procedures, and for which they may not be receiving adequate support. Common themes included the minimization of symptoms by family and friends; threats of job loss due to missed days; workplace discrimination; painful examinations by the doctor; painful intercourse with partners; loss of marriages, intimate partner relationships, and friendships; depression and suicidality due to constant pain; being labeled a

hypochondriac; feeling alone and isolated due to symptomatology; dealing with a dismissive medical community unwilling to legitimize symptoms; constantly being compared to other women who were able to manage their periods; made to feel like less of a woman due to being childless and infertile; and anger over tax breaks for children; when participants felt the money could also be allocated to finding a cure for endometriosis. Truth be told, I have experienced every single one of these things, and so have countless women diagnosed with endometriosis. However, the most pertinent and disturbing at the time was something known as “GP Trauma” (p.6). This is the process of quite literally being passed over by your general practitioner, symptoms dismissed and concerns trivialized. And that is exactly what played out in the previous encounter. While it was my last experience with GP trauma, I would later graduate to specialist trauma.

By January 2010 I had settled quite snugly into my new efficiency. When lying in my full-sized bed, I could literally reach the chest of drawers on the right side and the dresser on the left without getting up! While this may seem like an extraneous detail to some, it became very important within a month of relocating, as the timing of the move coincided with the implementation of this new birth control regimen. Within a month, I knew in my gut—the place adjacent to all the problem areas!—something was awry. I felt as though I needed to stop taking this medication, but was uncertain about how to proceed.

Fortunately, one of my professional colleagues had been a nurse for many years before becoming a mental health clinician. I approached Debi one afternoon and asked if we could talk. As I disclosed my apprehension over the growing body of symptoms and my own growing body from the progesterone birth control, which causes significant weight gain among other things, she recommended that I contact my doctor and go in for another consult to discuss my concerns.

When I called the doctor's office and the front desk staff inquired about the nature of the appointment, I began to explain my distress over the medication and its numerous side effects. She interrupted me abruptly by saying, "Just stop taking it."

Being young, naïve, and easily intimidated, I agreed and hung up the phone. The day after I stopped taking the birth control, I awoke in so much pain that I could not reach the bottle of Ibuprofen on the chest of drawers right next to me. In the months and years that followed I would experience this level of pain many times over, but this was the first time I had ever felt it. I was incapacitated. The pain didn't even leave room for anger or fear. It filled me almost as entirely as I had filled my little efficiency. And life as I knew it was over.

Debi continued to work diligently behind the scenes on my behalf after our conversation. She was the first to recommend that I begin seeing a fertility doctor. She started asking her connections within the medical community for recommendations and referrals for physicians with this specialty that were in my insurance network. In early March 2010, she gave me the contact information for Dr. Bundren an MD specializing in gynecology and fertility. Timidly, I dialed his number and made an appointment with the fourth OBGYN in a year and a half.

Upon arrival at my appointment, I was handed a checklist. It would be the first of many. These were not the typical inquiries about cancer, hypertension, and high blood pressure to which I was accustomed: they were specific to female fertility and endometriosis. Pain before and during periods: check. Fatigue: check. Painful urination during periods: check. Painful bowel movements during periods: check. Other gastrointestinal upsets such as diarrhea, constipation, nausea: check. Allergies: check. Chemical sensitivities: check. Frequent yeast infections: check. Excessive bleeding: check. I was checking every box with a growing awareness that something

was *actually* awry. Strangely, this didn't produce fear, but rather a feeling of relief washed over me—relief that someone might know what it was and how to treat it effectively.

After reading my responses and family history, Dr. Bundren walked into the room and stated, “I want to do a pelvic ultrasound right away. A Pap smear won't tell the story.” He was the first doctor I had seen who suggested this. A few moments later I was lying on the examination table staring at a black and white screen displaying my reproductive organs. They were a mess. The ovaries were covered in the typical webbing associated with endometriosis, and the fallopian tubes were twisted and distorted. In fact, the left tube was wrapped completely around the left ovary, that was also plagued with a growth the size of a golf ball. In addition, the doctor pointed out the presence of multiple polyps in the pelvic area. In fact, Dr. Bundren expressed concern over endometrial invasion of both my kidneys and gall bladder as well. His preliminary diagnosis? Endometriosis. His recommendation? Surgery within the week, and at the latest, within the month.

After the ultrasound was completed, the doctor and nurses filed out of the room. I numbly got dressed and walked across the hospital to the outpatient surgery reception area awaiting paperwork and instructions. As if on a reel, I replayed the images I had seen and the words I had heard replaying in my mind. It now had a name. Right then I heard mine.

“Peña?” I walked up to the desk.

“Okay, hun, I have you down for a laparoscopy, hysteroscopy, and chromotubation on March 26th, 2010 at 8am. Now, you are goin' to need to show up at least one hour before you're scheduled, so that you can be prepped for the OR. This is considered an outpatient procedure, so don't worry about bringing a change of clothes or anything like that. But you will need a driver,

because you will be under anesthesia and incapable of drivin'. Now, do you have someone in mind who can bring you and take you home?"

"Yes, ma'am. My mom can bring me and stay here throughout the procedure."

"Oh, great! Then we'll give her your clothes for safe keepin' while you're in the OR."

"Okay" I said weakly. I could feel myself getting light-headed and a little nauseous as the doors to the Med Surge unit kept opening and closing to reveal rows of beds filled with patients heading into and out of surgery. With every closure, the smell of band-aids, surgical tape, antiseptic, and sickness whooshed out into the waiting room.

"Oh, I almost forgot, I need you to drink as much of this as you possibly can the night before." A gallon of "bowl prep" thudded onto the counter. Ugh. Speaking of the smell of sickness! From then on I tried to block both the bowl prep and sick bay from my line of sight.

After finalizing insurance information and signing release paperwork, I left feeling a strange mixture of fear and relief. At least I was finally going to get help and have resolution! The purpose of these procedures was first diagnostic in that the laparoscopy is the only way to determine the presence of endometriosis. Dr. Bundren was quite confident that it was endometriosis, so he was also viewing the surgery as both exploratory, to evaluate the extent to which endometriosis may have invaded or distorted the organs, and reparative in that some time would be spent lasering off any growths, polyps, or endometrial oblations.

In a spectacularly unsurprising turn of events, the bowel prep the night before may have actually been worse than the procedure—the jury is still out on that one! Upon arrival at the hospital the morning of the surgery, I was admitted and given the standard-issue gown and words of encouragement. Dr. Bundren, my surgeon, came to get me and walked with me into the OR. As I lay on the table staring up at the bright lights, I obediently began counting backward from

ten as instructed by the surgical team while they increased the anesthesia and placed the oxygen mask over my nose and mouth. I cannot recall the number I reached. All I remember is that I was dreaming of the beautiful beach in Oaxaca, Mexico I once visited, and longing for the solace of my favorite hammock which stood in stark contrast to the sterile surroundings of the hospital that day.

I awoke in pain. The cheerful nursing staff were chattering and laughing around my bed telling me,

“Hun, you woke up like a teenager! You were in the fetal position.” I found it less than amusing. I was discharged that same day after demonstrating to my nurse I could urinate. Trust me, after having a catheter, pain from the procedure, and grogginess and nausea from the anesthesia, urination was quite an accomplishment! My mom drove me home to my little efficiency, and I lay in bed uncertain of what would transpire in the days ahead. Most of my focus was reduced to recovering.

My post-op appointment told the story with painful precision. While showing me nauseatingly graphic surgical photos, Dr. Bundren carefully explained the surgical procedures he’d performed and the discoveries he’d made a week prior. Finally, he closed my chart. Placing his hands in the pockets of his white coat, looked me in the eyes and said,

“You have stage three endometriosis. It’s an advanced case, Carma. Your left fallopian tube is completely non-functional. It was not only wrapped around your left ovary, it had attached itself to your kidney. Now, I *was* able to untangle it, dislodge it from your kidney, and laser off a lot of the endometrial growths that I found in the pelvic area, but it *had* spread to your bladder. For that you’re going to need to see a urologist because we certainly don’t want you to

run into any issues down the road with endometriosis invading the ureter⁶. Based upon what I found, I highly recommend that you start a course of Lupron Depot to keep your ovaries quiet in the six months following the procedures I just performed.”

He held my gaze and watched as the words washed over me. I remember thinking he had kind eyes. That was a first for one of my doctors. He was also the first to hear *me* and *help* me—the first to confirm I was not crazy, I was *correct*. His belief and validation of my medical symptoms emboldened and empowered me. Ultimately, my interactions with Dr. Bundren would begin to reshape my expectation of other medical professionals in the years to come.

Despite feeling stunned and awash in both fear and relief, endometriosis was a name I knew well. I had a precedent and frame of reference for it. The terms Dr. Bundren was using were familiar to me. I had also heard of Lupron Depot before, from my mother. She too had undergone this form of chemotherapy following a similar procedure to manage her endometriosis. Her experience was highly negative, so my consternation grew despite my trust in this doctor.

When I expressed these concerns to the doctor and his nursing staff, one of his nurses sought to assuage my apprehension by describing the process in the following manner, “Honestly, it’s as if your ovaries are in a hammock sipping a drink. While the side effects can be difficult to deal with initially, the long-term benefits will outweigh the immediate disadvantages.” My mind drifted back to the hammock in Mexico about which I still day dream, and I decided to give it a try.

No checklist in the world, no matter how thorough, would have been able to predict what would transpire for me personally, professionally, and medically in the upcoming months and

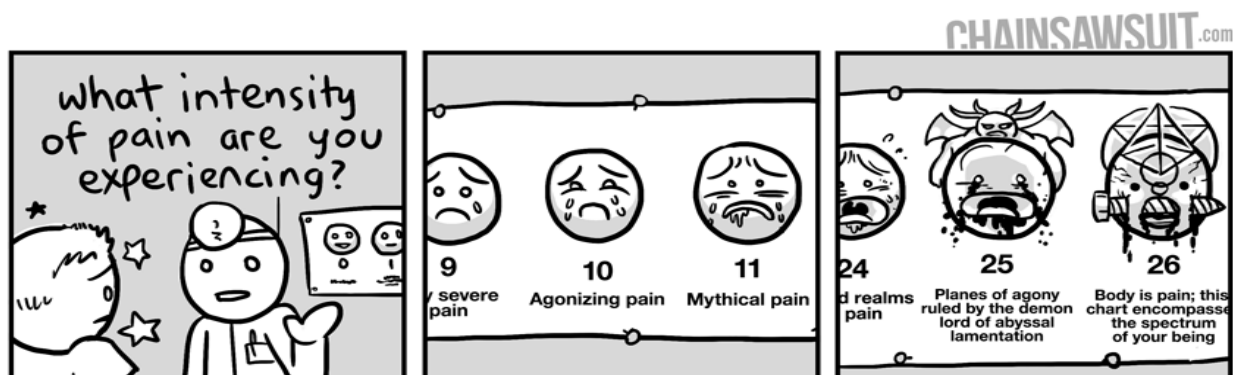
⁶ <http://www.healthline.com/human-body-maps/ureter>

years; for that I am grateful. Then it was enough to take things day by day, treatment by treatment. I was optimistic that things were improving for me despite the fact that I too had fallen prey to the dreaded endometriosis. While I had not escaped its clutches, I was determined to manage it with grace and strength. However, I would be lying if I did not own the fact that I felt diminished by it and disillusioned with God. By then, it was *quite* clear to me that He did not always prevent pain. So, as the roller coaster made its first gut wrenching descent, adult Carma found she could pray for nothing more than His peace.

~ Psychological Insights & Therapeutic Thoughts ~

Making Meaning of the Mess

One of the unique features of endometriosis is that symptomatology and staging do not always correlate. Consequently, someone with stage-one endometriosis may have severe symptoms, whereas someone with a stage-four medical presentation may have few to no indicators at all. In my case, the pain and level of severity corresponded. It was not until after the surgery that I began to put the pieces together and understand the picture more comprehensively, and it all started with a pain chart and symptom checklist, something similar to what is pictured below.



Clearly laughable, this comic is merely a lighthearted approach to the very complex issue of endometriosis pain, transient or persistent. In recent years, more and more research has been

dedicated to understanding the ways in which our mental health and overall functioning is impacted by a) medical conditions, especially in the presence of chronic pain, or illness, b) remaining undiagnosed or incorrectly diagnosed, c) pain management regimens that may include psychotherapy in their list of interventions, d) compartmentalization of pain and its (in)effectiveness and, e) the impact of religion and spirituality on the management of chronic pain.

Let's take a deep dive down through the *Doorway to the Deep*, beginning with a short history lesson. The field of mental health has undergone multiple theoretical shifts over time. Initially, issues of mental health which arose either periodically or persistently in a person's life were attributed to spiritual defects. As the field of psychology and psychiatry evolved, however, abnormalities were later linked to the internal psyche which gave rise to psycho-analytics and psychotropic medications. This era was largely experimental. (See chapter two for more detailed research). Over time, this ideology gave way to behaviorist psychology of which B.F. Skinner was a key figure⁷. From behaviorism, cognitive-behavioral therapy was developed and pioneered by psychologist Albert Ellis and psychiatrist Aaron Beck. However, in the late 1950s, a consortium of cognitivists, philosophers, scientists, linguists, and mathematicians converged at the Massachusetts Institute of Technology, and cognitive psychology was born. Since that time, terms such as "brain-based behavior" and "neurobiology" have risen to preeminence in the therapeutic community.

Fundamentally, neurobiology is the study of nervous system cells and their organization or arrangement into functional circuitry capable of processing information and mediating behavior⁸. Research within the field of psychology and psychiatry was indicative of deficits in

⁷ https://youtu.be/I_ctJqjlrHA

⁸ <https://www.sciencedaily.com/terms/neurobiology.htm>

both the understanding and treatment of mental health disorders. Many of the outcomes and conditions could not be explained clinically. Therefore, a radical shift was needed in the understanding of their origin, development, and treatment over time. Enter neurobiology as both a contributor to and determinant of behavior, as well as an area of clinical intervention.

While the introduction of neurobiology into the field of mental health is relatively recent, the medical field has long since utilized this concept in theory and practice. Its understanding and application is particularly relevant in the treatment of patients with chronic medical conditions, specifically chronic pain. Common terminology include concepts such as “pain pathways,” which refers to the way the brain processes and interprets the sensation of pain, as well as the subject of “neuroplasticity” or “brain plasticity,” an umbrella term encompassing both synaptic and non-synaptic plasticity⁹. Ultimately, neuroplasticity refers to changes in the synapses and neural pathways related to alterations in thinking, emotions, behavior, environment, and neural processes, as well as to any fluctuations resulting from bodily injury. That said, the concept of neuroplasticity has now replaced the previously-maintained position that the brain is physiologically static. Research is expanding and exploring how and in what way the brain may change over the course of a person’s lifetime (Pascual-Leone, A., Amedi, A., Fregni, F., & Merabet L. B., 2005).

Enter the connection between neurobiology and mental health. This body of research served a dual purpose. First, it lent credence to the cognitive-behavioral theoretical framework by adding neurobiology, for it was now clear that there was a scientific link between neurobiology and mental health. It demonstrated definitively that negative experiences could have an impact upon the brain and thus thought, and could therefore improve or change with

⁹ <http://www.brainhq.com/brain-resources/brain-plasticity/what-is-brain-plasticity>

positive intervention. Second, it created the potential for “cognitive reprocessing” in its most fundamental form. This concept comes from cognitive processing therapy, a derivative of cognitive behavioral therapy. Simply stated, it is a therapeutic intervention designed to allow a person to reprocess a traumatic event for the purpose of alleviating psychological pain arising from a maladaptive understanding of the occurrence. This work has become widely used and accepted and is considered a “best practice” within the therapeutic field, and is even recognized as such by managed care companies, which often fund these types of treatments.

As the field of mental healthcare expanded to include neurobiology, research on the reciprocal relation between pain and mental health rose to fore. In 2009, a study was conducted on patients who had been formally diagnosed with severe chronic obstructive pulmonary disease (COPD). Outcomes indicated that of the participants, twenty-two percent struggled with at least mild depressive symptoms as measured by a score of fourteen or greater on the widely-used psychometric measure the Beck Depression Inventory (BDI), and seventeen percent of those were taking antidepressant medications.

Professor David Goldberg of the Institute of Psychiatry, London, UK, reports that the rate of depression in patients with a chronic disease is almost three times higher than normal. He explains, ‘Depression and chronic physical illness are in reciprocal relationship with one another: not only do many chronic illnesses cause higher rates of depression, but depression has been shown to antedate some chronic physical illnesses’ (Collingwood, 2016).

This body of research suggests that mental health can have an impact on our bodies in the same way that medical conditions can have an impact on our mind. While working with children in highly chaotic environments who often witnessed and/or endured traumatic events, I observed

predictable patterns in reported medical conditions—specifically asthma. As I began to research the prevalence of asthma among this population, I discovered that there is a high correlation between children who have survived these incidents and the diagnosis of asthma.

A 2008 pilot study was launched to study this association. Parents of children aged seven-to-seventeen were recruited to participate from an inner-city asthma clinic. Various psychological measures were administered to the parents to rate the severity of PTSD symptoms, asthma symptoms, and the healthcare utilization. Outcomes indicated that “posttraumatic stress disorder symptoms were found to be significantly related to asthma severity, quality of life, and health care utilization” (Vanderbilt, et al., 2008). Ultimately, while causation of asthma has never been proven or attributed to trauma, it may be a very common physiological reaction to it.

From the synthesis of cognitive behavioral therapy and neurobiology or brain-based counseling, the concept of pain management crossed over to the field of psychology (Arden, 2014). While the experience of pain is very real biologically, certain alterations in thinking, behavior, emotions, environment, etc., have the ability to alter the experience of pain emotionally. Some methods of nonpharmacologic intervention include controlled breathing, active listening, patient education, relaxation strategies, changes in bed positioning, application of heat and cold, modification or reinforcement of pain control behaviors, as well as the implementation of an exercise program and therapeutic massage.

However, it is time for an important disclaimer. Results are always case specific and should be pursued only at the recommendation of qualified medical professionals and while under their care. There is also an important *distinction* to make at this juncture. The aforementioned interventions as applied in the context of a pain management program are not cures. They are merely methods of managing an ongoing problem.

Employed as both a primary and ancillary treatment in *non-life threatening medical conditions*, these interventions overall have proven beneficial per many patient reports and according to numerous studies. The bibliography lists some of these.¹⁰¹¹¹² Consequently, a growing number of medical pain management programs include behavioral therapy in tandem with psychopharmacology. In fact, many psychotropic medications are used for pain management and vice versa. For example, take the drug class *benzodiazepines*. Benzos were the accidental creation of Leo Sternbach in 1955. Since then, they have been meticulously developed to contain “sedative, hypnotic, anti-anxiety, anticonvulsant, and muscle relaxant properties. They work by enhancing the effect of the neurotransmitter gamma-aminobutyric acid (GABA) - which is responsible for reducing the activity of neurons that cause stress and anxiety” (Nordqvist, 2016). Currently benzos are prescribed for seizures, insomnia, panic attacks, alcohol withdrawal, and generalized anxiety disorder. This mixture of medical, mental health, and substance abuse diagnoses suggests that all three may be treated by targeting the same area of the brain and therefore that there is a greater interconnectedness of the human body and brain than was historically believed. In turn, the compartmentalization of pain—whether physical or psychological—has been discredited.

As a Protestant or Christian, I have read the Bible many times and value it as a central source of truth. You will continue to see my religious, spiritual, *relational* struggles with the divine throughout this text. But always, I return, even if, and especially when I was attempting to

¹⁰ Tyrer, P., Tyrer, H., Morriss, R., Crawford, M., Cooper, S., Yang, M.,...Barrett, B. (2017). Clinical and cost-effectiveness of adapted cognitive behaviour therapy for non-cardiac chest pain: Multicentre, randomised controlled trial. *Nottingham ePrints*. Retrieved from <http://eprints.nottingham.ac.uk/id/eprint/40934>

¹¹ Fales, J., Palermo, T.M., Law, E.F., & Wilson, A.C. (2015). Sleep outcomes in youth with chronic **pain** participating in a randomized controlled trial of online cognitive-behavioral therapy for **pain management**. *Behavioral Sleep Medicine*, 13(2), 107 – 123. Doi: 10.1080/15402002.2013.845779

¹² Morley, S., Eccleston, C., & Williams, A. (1999). Systematic review and meta-analysis of randomized controlled trials of cognitive behaviour therapy and behaviour therapy for chronic pain in adults, excluding headache. *Pain*, 80(1-2), 1 – 13. [http://dx.doi.org/10.1016/S0304-3959\(98\)00255-3](http://dx.doi.org/10.1016/S0304-3959(98)00255-3)

understand and cope with the complexities of chronic pain. It was that pursuit of answers that led me to the Biblical basis for the concept of “unity in the body” which is alluded to in I Corinthians 12. While this passage refers to a larger “body of believers” the example of the body is used to demonstrate the importance of every part, as well as the profound impact each has on the other. “If one part suffers, every part suffers with it; if one part is honored, every part rejoices with it” (v.26).

Much more could even be said of the way in which we are interconnected as human beings, but that is not the primary intent of this discourse. The core of this commentary is to demonstrate the reciprocal relation between medical and mental health conditions for the purpose of normalizing the symptoms of both that often arise concurrently throughout our lives.

Another component that was addressed in chapter two has been added to many pain management assessment questionnaires: spirituality. Currently, many of the initial assessment packets for pain management programs include checklists of their own for this dimension. Often their questions center on connectedness to not only a set of beliefs (*spirituality*), but also a supportive community of faith (*religion*).

In order to better understand the relation between religion/spirituality (R/S), physical health, and mental health, Rippentrop, Altmaier, Chen, Found, and Keffala (2005) conducted a study on one hundred and twenty-two patients suffering with chronic musculoskeletal pain. Conceptualizing R/S as a multidimensional factor, these researchers implemented the Brief Multidimensional Measure of Religion/Spirituality as a tool to measure outcomes. The findings are as follows:

Pain patients' religious and spiritual beliefs appear different than the general population (e.g. pain patients feel less desire to reduce pain in the world and feel more abandoned by

God). Hierarchical multiple regression analyses revealed significant associations between components of religion/spirituality and physical and mental health. Private religious practice (e.g. prayer, meditation, consumption of religious media) was inversely related to physical health outcomes, indicating that those who were experiencing worse physical health were more likely to engage in private religious activities, perhaps as a way to cope with their poor health. Forgiveness, negative religious coping, daily spiritual experiences, religious support, and self-rankings of religious/spiritual intensity significantly predicted mental health status. Religion/spirituality was unrelated to pain intensity and life interference due to pain. This study establishes relationships between religion/spirituality and health in a chronic pain population, and emphasizes that religion/spirituality may have both costs and benefits for the health of those with chronic pain (p. 311).

This study suggests there may be positive outcomes associated with religious practices or some sense of spirituality—even if the benefit is primarily mental and not physical improvement. Even recovery communities such as 12 Steps underscore this, recognizing the importance of a higher power—whatever form that may take. Like many who struggle silently with cravings associated with the disease of addiction, those struggling with the unrelenting pain of an invisible medical condition known as endometriosis may also draw strength from a religious or spiritual connection. While R/S *may* have no bearing upon pain intensity or upon the degree to which the pain inhibits the ability to perform activities of daily living, it does have the power to impact the mental/spiritual state and neuroplasticity of the brain.

However, at the risk of redundancy, I would like to reiterate that to ensure effectiveness in coping with ongoing pain, challenging medical conditions, remaining undiagnosed, or incorrectly diagnosed, these religious/spiritual communities need to promote agendas that are not

only true to members' core beliefs, but also helpful to them in becoming a fully functioning individual. The cross section of these concepts cannot be overstated; therein lies the key to creating deeper meaning and resiliency when experiencing pain and suffering. Conversely, imbalance in what is believed by the individual to be true *and* helpful tends to create even greater distress and regression.

To conclude, there is great value in conceptualizing the physical, mental, and spiritual components of human beings as interrelated. Studies provided in this chapter and a growing body of research imply that these domains may have an impact on each other. While it is beneficial to study each domain for its unique features and contributions, and to better understand, enhance function, or treat deficits, it must be recalled that no domain is fully independent of another. It is for this reason that remaining undiagnosed in the face of increasing pain and symptoms was not only physically, but also psychologically and spiritually draining to me, as it is for many who have endometriosis. Intuitively, I knew something was wrong as is often, but not always, the case when something is medically amiss. And *my* experience of this was relatively short-lived from the time I sought out medical attention to the time I was diagnosed with endometriosis. Many people go *years* without a definitive diagnosis or prognosis. It is in these latter scenarios that attention to all three domains becomes not beneficial, but vital.

Take some time to conduct the following wellness assessment listed as a free online resource at <http://www.testwell.org/>. While there are more than spiritual, emotional, and physical domains included in this evaluation, each could conceivably be subsumed within these larger umbrella terms. As you drop through the Doorway and begin exploring the Deep, consider these questions.

- a) Were you surprised by your scores? If so, which ones and why?

- b) If your scores are lower than expected, what is your plan of action for increasing your level of self-care in this/these area(s)?
- c) What can you do *today* to improve your scores and thereby enhance your spiritual, emotional, and physical well-being?

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